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THE UNIVERSITY OF ALBERTA

THE FAMILY PERSPECTIVE ON DYING AT HOME

by

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A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH
IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE
OF DOCTOR OF PHILOSOPHY

DEPARTMENT OF EDUCATIONAL ADMINISTRATION

EDMONTON, ALBERTA
SPRING, 1987

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DEDICATION

To the dying patients and families
who shared their experiences with me.

ABSTRACT

The focus of this study is on one dimension of hospice care, the experiences of the family member who is primarily responsible for the care of the person dying at home. The researcher enquired not only into the experiences of the caregiver but also into the meaning of the experiences of eight key informants and nine ancillary informants.

The study is inductive and descriptive. Data were collected from unstructured, taped interviews with the informants in their homes or settings of their choice, from observations of contextual and non-verbal indicators related to the experience and from documents made available to the researcher.

Analysis of the data was guided by Glaser and Strauss (1967), Bogdan and Biklen (1982) and Field and Morse (1985).

Themes are reported under the emergent categories of Informants' Expectations of the Health Care System, Informants' Perceptions of the Health Care Professional, Informants' Coping Strategies, Informants' Support Matrix: What is Available and What is Needed, and Emotional Costs/Emotional and Other Benefits of Caregiving as Perceived by Informants. It was discovered that the category that was of primary importance to all informants was the Need for Information. The Need for Information was therefore examined and described in detail.

Hypotheses about the caregiving experience are submitted and a suggested change in the working definition of Hospice/Palliative Care is demonstrated to be supported by the data. Practical tools for the clinician (Family Caregiver's Assessment Form) and for the administrator/researcher (The Responsive Evaluation Framework) are offered for consideration. Findings from the inquiry are used to 'ground' the Assessment Form and the Evaluation Framework in the patient/family caregiving experience.

Recommendations from the study are directed to the professional clinician, administrator and educator who are directly or indirectly involved in providing palliative care to patients and family caregivers.

ACKNOWLEDGEMENT

I am indebted to Margaret Voice for her patience, encouragement and meticulous typing. She has the knack of turning chaos into order.

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Chapter 1

OVERVIEW OF THE STUDY

Introduction

A need exists to develop methods of evaluation for hospice/palliative care programs that more accurately reflect the philosophy and goals of the hospice way of caring for the dying (Mount and Scott, 1983). Recent attempts to measure the effects of hospice programs have not been successful at quantifying or describing the dimensions of psychosocial change demonstrated by terminally ill patients and their families (Greer et al., 1983; Kane et al., 1984). Alternative methods of assessing responsive quality care for the dying are required. The source of a key piece of the missing information is the client, the patient and family living through the experience.

The focus of this study is an inquiry into one dimension of hospice care; the experiences of the family member who is primarily responsible for the care of the person dying at home. The findings provide basic information about caring for the dying as it is experienced by those directly involved. The purpose of the study is to present the information gathered about the positive and negative aspects of the experience. The findings are presented within an evaluation framework. The evaluative framework developed is responsive to the family experience and is consistent with hospice philosophy and organizational goals.

In order to set the present study into the hospice context it is necessary to provide a brief overview of the development of the hospice way of caring for the terminally ill patient and his family. Part of the following overview is from _Comprehensive Care for the Dying: An Organizational Model_, a study done by the author in 1980.

Background to the Study

Health care institutions that are presently providing terminal care for the majority of people in western society have in recent years come under criticism by the public and by a number of professionals working in the health care system (Saunders, 1967; Kubler-Ross, 1969; LeShan, 1977; Wald et al., 1980; Fraser, 1985). Adler (1976:32) described the current situation for the terminally ill in many acute care settings:

> In the twentieth century, home and family have been replaced by nursing home and hospital as the site where most people die. The fear that death will be unnatural and alien is surely accentuated when sickness is accompanied by removal to an unnatural and unfamiliar place where accomplishments, acquisitions, and identity must be left behind.

Although the philosophy undergirding most health care institutions is based on a belief in the well-being of the whole person, including unholding quality of life for the dying, the literature and personal experience as a family member and professional caregiver within the system demonstrate a discrepancy between the stated philosophies and the day-to-day activity within the institution, particularly in the sphere of terminal care.

It has been charged that the depersonalized, clinical routine of the hospital, the institution in which most North Americans will die, has been structured to meet professional requirements rather than planned to meet the needs expressed by the clients they serve (Storch, 1977; Mount, 1980). This indictment may seem harsh. However, the clear, if unwritten, goal of the traditional institution is to cure the patient by investigating, diagnosing and treating the disease. The terminally ill, for whom there is no cure, are perceived as embarrassing and frustrating failures (Kübler-Ross, 1967; Lifton and Olsen, 1974). No one suffers more in this environment geared toward cure than the dying patient.

Many health care professionals believe that patients and their families would prefer to live out their time together in the familiar setting of their own homes (Zimmer et al., 1984). Being actively involved in the care of the dying person is thought to ease the pain of the loss experienced by the family (Craven and Wald, 1975; Hampe, 1975).

Care for the dying, however, can be difficult even for experienced professional caregivers who have the support of a multidisciplinary team within a fully equipped hospital (Lanara, 1981). How much more difficult it could be for inexperienced family members, already feeling the stress and pain associated with the loss of someone they love, to bear the extra burden of caring for a relative dying at home.

The literature on caring for the dying reflects the values-laden complex nature of the subject of death and dying. As Ariès (1981:586) noted, in our time, death is often perceived to be "an accident, a sign of helplessness or clumsiness that must be put out of mind," or it is circumvented with "rhetoric and beautification." However, when confronted with the dying patient, the caregiver is presented with a dilemma of crisis proportions. The potential is there, it seems, for lay and professional caregivers to experience what may be considered the most difficult and/or the best of human emotions. In response to the inadequate and distressing state of the art of terminal care, an alternative concept of care called Hospice resurfaced with renewed vigor in 1967.

Hospice Care Defined

Indicative of the differing philosophical beliefs of people who work and study in the field of caring for the dying is the difficulty of reaching consensus about definitions of terms. Terminal care, supportive care, palliative and hospice care are terms used to describe programs designed to care for dying patients.

The following definition is taken from Palliative Care Services in Hospitals: Guidelines (1981:2), a document prepared by a multidisciplinary work group commissioned to develop guidelines for palliative care services in Canadian hospitals.

> "Palliative care" refers to programs or services that provide care to those patients for whom treatment aimed at cure and prolongation of life is no longer appropriate but for whom therapy aimed at improving the quality of the remaining life is the primary objective. Palliative care offers therapeutic services designed to address the physical, psycho-social and spiritual needs of dying patients and their families.

The National Hospice Organization (U.S.A.) defines hospice as follows:

> [Hospice is] . . . a medically directed, nurse coordinated program, providing a continuum of home and inpatient care for the terminally ill patient and family. It employs an interdisciplinary team acting under the direction of an autonomous administration. The program provides palliative and supportive care to meet the special needs arising out of the physical, emotional, and spiritual, social and economic stresses which are experienced during the final stages of illness and during dying and bereavement. This care is available 24 hours a day, seven days a week.

Because hospice is the term of choice in literature from Britain, the United States and parts of Canada, the terms palliative care and hospice are used interchangeably in the initial phases of the study to connote comprehensive, quality care for the dying and their families.

Hospice: An Historical Perspective

Sandol Stoddard (1978), in her book called The Hospice Movement: A Better Way of Caring for the Dying, presents a most interesting description of the development of hospital and hospice, as two institutions for terminal care. Stoddard describes these two institutions as two divergent branches coming from the same root, the essence of which is captured in the Latin word "hospes" (see Figure 1). "Hospes" means both host and guest, a process or interaction between human beings.

The words hospitality, hospitable, hospice and hospital are derivations from the same root "hospes," but as Stoddard writes, since the Reformation and the closing of monasteries formerly charged with the care of the sick and the dying, the ancient notion of hospitable care for the sick and the dying has undergone considerable change. In hospital, the branch that flourished since the Reformation, institutionalized care which was formerly provided by religious communities came increasingly under government and corporate control. Stoddard (1978:53) claims that at present hospital care is so "entangled in bureaucratic procedure demanding so much paper work of most physicians [and other health care personnel] that time and energy they can give to patients is sorely limited." The hospice, during the flourishing of cure-oriented hospitals, for the most part, went underground

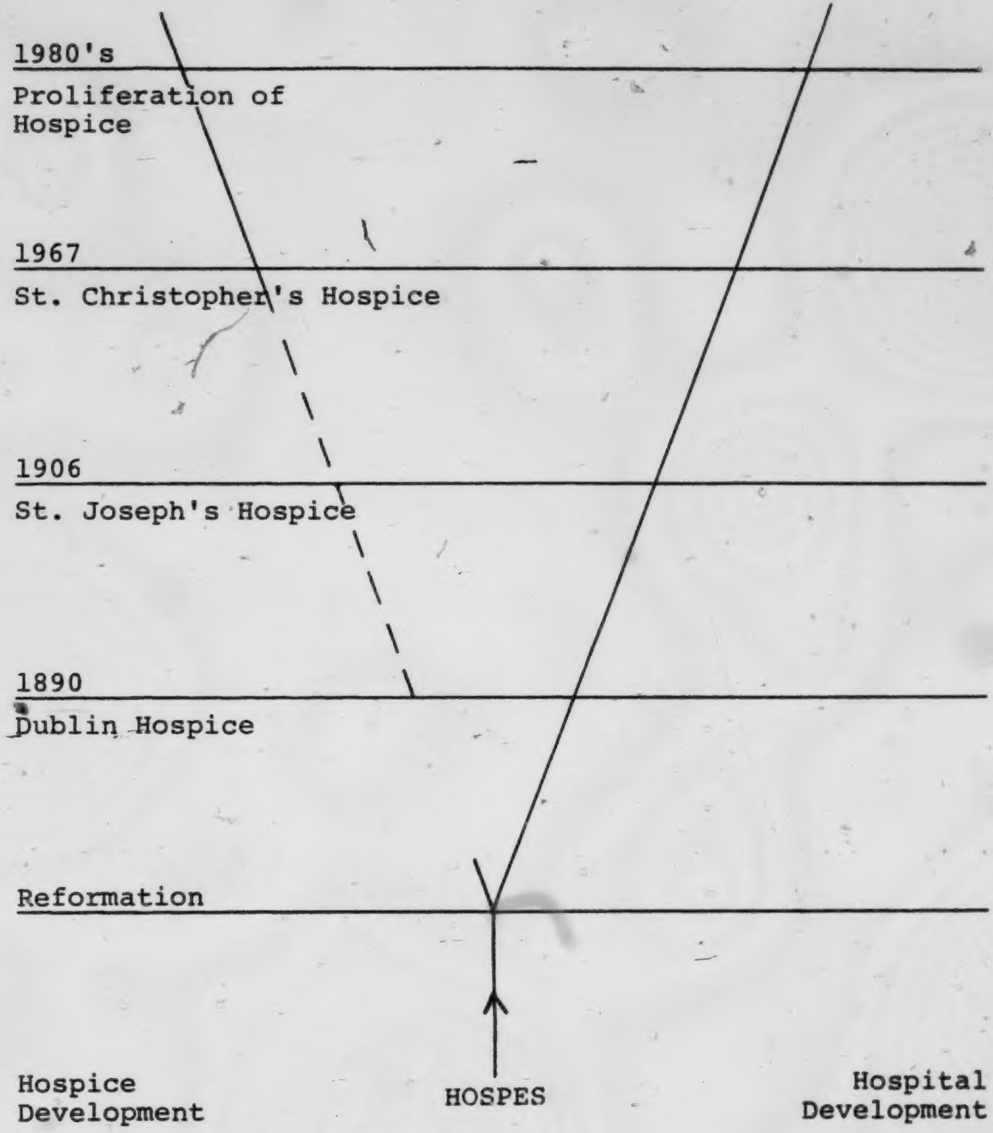
1980's
Proliferation of Hospice
1967
St. Christopher's Hospice
1906
St. Joseph's Hospice
1890
Dublin Hospice
Reformation
Hospice Development
HOSPES
Hospital Development

Figure 1

Growth of Alternate Institutional Care Facilities
for the Terminally Ill
(From: McHutchion, 1980)

with only a few notable exceptions.

One such exception to hospital care was a hospice founded in Dublin in the late nineteenth century by Sister Mary Aikenhead, a co-worker of Florence Nightingale. In 1906, St. Joseph's Hospice, established by the English branch of the Dublin Order surfaced and it in turn has been a major influence on Saunders who is considered a pioneer in the field. Saunders founded 'St. Christopher's,' a hospice which opened in 1967 in Sydenham, England.

The work at St. Christopher's Hospice has been the acknowledged basis for much of the recent development of institutional as well as community based programs designed to care for dying patients and their families. Saunders is generally recognized by professionals in the field of hospice and palliative care as the pioneer in the work of humanizing care for the dying. Saunders is a nurse, a social worker and a physician and as such reflects the multifaceted, multidisciplinary foci of hospice care for the terminally ill.

Because of the profound and far-reaching influence of St. Christopher's Hospice and its founder, Cecily Saunders, the organizational components of St. Christopher's Hospice are used to provide further information about the hospice concept.

Administrative Aspects: The Essentials of Hospice Care

Although hospice care is becoming relatively well known and practiced throughout the world, there are widely diverging notions of the way that the hospice concept is to be translated into service. As Saunders (1981:93) notes:

> To many people, a hospice is an institution concerned with the terminally ill, usually cancer patients and their families. That is a simple, neat definition but a limited one. Implicit in the hospice concept is that care should be available to a mixed group of patients with terminal illness or progressive disease when the acute hospital no longer has anything to offer and when the caring responsibility can no longer be met by the family or the community.

Because of the differing opinions amongst professionals and lay people about the structure and processes of hospice care it is useful to reiterate the elements that have been spelled out by Saunders and the staff at St. Christopher's Hospice, England in their 1978 Annual Report. The content has been arranged in the following way for the sake of clarity and brevity.

The St. Christopher's Hospice Concept of Care

The population: Breadth and depth of service.

Although the current interest in hospice care in the U.S.A. (and Canada) is especially concerned with 'the dying cancer patient and his family,' a good community is usually a mixed one and hospices have included among their concern those with long-term illness, chronic pain and, in some cases, frailty associated with aging.

The unit of care is the patient and his family. Both the patient and family may need support, not only in meeting physical demands but also in their own search for reality and meaning.

Bereavement follow-up is considered to be part of hospice care in order to identify those who are likely to be 'at risk.' Support is given to the family in cooperation with the family doctor and any local services which can be involved.

The philosophy permeating hospice care. There is a belief in the need for competence and compassion amongst all personnel. An efficient and approachable administration is required to give security to patients, families and staff. Efficiency is both comforting and timesaving. So far (according to the 1978 St. Christopher's Report), hospices have shown that their operation is cost effective as well as appropriate and humane.

Staffing: Coordination and commitment. Management by an experienced clinical team integrated into the work of the whole medical community is seen as necessary for effective continuity of care.

Skilled and experienced team nursing calls for confident leadership by the ward sister (head nurse). Easy communication among its members is necessary to meet the multivariate needs of patients and family.

The full inter-disciplinary staff meet frequently for discussion. The doctor does not relinquish his or her clinical responsibilities but a member of another discipline may sometimes assume leadership for a particular patient or family. Staff must be prepared for the cost of commitment and the search for meaning that is associated with caring for the dying. Devotion has been an outstanding characteristic of past and present hospice care.

The focus of care. Understanding control of the symptoms common to terminal illness, especially pain in all of its aspects, helps staff to help patients live to their maximum potential. Unexpected remissions and/or the possibility of further active treatment are welcomed by staff and patient alike.

Research. Methodical recording and analysis of records are used to monitor clinical practice and, co-ordinated with relevant research where possible, lead to soundly based practice and teaching.

Teaching. Teaching in all aspects of terminal care is a hospice mandate. Special units are a resource, stimulating initial interest, giving experience and passing on tested knowledge to others in both generalists' and specialists' fields.

Outreach. A Home Care program, active or consulting and involving all the relevant disciplines, is developed according to local circumstances so that it can be integrated with the hospitals, the family practice and the Hospice's own beds.

Evaluation. Hospice care offers help to its patients and their families as they seek to understand and exercise their proper responsibility. It involves them in decisions and aims to support them in making realistic choices for themselves. The criterion of success is found in what the patient can accomplish in the face of his deterioration or dependence and in how the family lives on.

Summary. Although the forgoing description of hospice care obviously comes from an institutional perspective, it is notable that early in the days of hospice development, Saunders saw the relevance of the hospice concept for application beyond the cancer experience and beyond the four walls of the institutional setting. In speaking of the principal goal of hospice Cecily Saunders (1981:93) sums up the primary hospice purpose. She writes:

> [The purpose of hospice is] . . . to provide the efficient, loving care that permits the patient to fulfill his or her potential in the remaining time. We try to give, or give back, the sense of community, of belonging, of personal worth that gave meaning to the patient's life—and to our own. The hospice offers hospitality to such a person and to his or her family and friends: if

> we have done our work well, the lonely journey can be turned into a safe peaceful one. This is equally true if the patient is in the bed of a hospice or at home.

Need for the Study

Hospice Care: Current Concerns

The hospice way of caring for the terminally ill sounds ideal and humane. However, writers and researchers in the field of palliative and hospice care are now being called to the task of moving beyond assumptions and personal biases. As Hospice enters its third decade of renewed growth and development, the value of hospice care must now be demonstrated. There has been an increasing demand for 'hard' evaluation studies of the hospice way of caring for the dying (Hannon and O'Donnell, 1984 and Greer et al., 1984). The criterion of success may no longer be solely measured on "what the patient can accomplish in the face of his deterioration or dependence and in how his family lives on" as suggested in the 1978 St. Christopher's Hospice Report as previously cited.

The Need for Responsive Evaluation

The state of the art in hospice care may be, however, beyond the research capabilities to quantify, measure and evaluate in the usual fashion. Mount and Scott (1983) describe the dilemma experienced by teams of researchers who are attempting to evaluate hospice care. Major empirical studies such as the American National Hospice Study reported by Greer et al. (1983) and Kane et al. (1984) are not able to measure any significant difference between hospice and traditional medical care for the dying yet evaluators are puzzled to find "hospice patients expressed more satisfaction with the care they received; and hospice patients' FCG's [family caregivers] showed somewhat more satisfaction and less anxiety than did those of controls" (Kane et al., 1984: 890).

Mount and Scott (1983), leaders in the field of care for the dying, warn of the danger of using inappropriate research methods to study the total effect of hospice care. The stakes are high, they claim, in these critical times of government scrutiny and subsequent policy and funding decisions. Mount and Scott (1983) claim that the most recent studies such as the American National Hospice study done by prestigious teams of researchers funded by government agencies, may not be using all of the necessary methods to truly evaluate the hospice effect.

Under the heading What should be measured to assess the impact of hospice care? Balfour Mount (1983:733-734) writes:

> Last weekend a young Italian lady with metastatic malignancy died within 1 hour of being referred to "hospice"—the palliative care unit of our teaching hospital. She was 35 years old and already comatose when the Emergency Room resident called. Among the ten anxious family members that crowded the waiting

> room when I arrived at 2:00 a.m. were those who demanded that she be resuscitated if she were to die and others who asked if there was still a chance of cure. She died less than an hour later, on the palliative care unit, her family around her. On leaving our hospice ward following her death the family commented gratefully that the experience had been one of the "most beautiful" they had had as a family. A major transition in less than an hour. As I drove home I thought of the National Hospice Study and realized that in all probability none of the differences "hospice care" had made that night would have been measured by the study. To have done so the study would have had to measure an increased sense of personhood and enhanced context of meaning, improved communication within the family and between family members and health care workers, lessened uncertainty and fear of the unknown, greater acceptance of the reality facing them, greater ability to express fears, doubts, guilts and anger, and the significance of being able to pray together, alongside the hospice physician and nurses. The National Hospice Study measures none of the above. It may be that excellence in hospice evaluation must await the development of new outcome measures.

The editorial by Mount and Scott (1983:735) ends as follows:

> Let us collect data using the outcome measures described in this study [American National Hospice Study] but let us also explore other methodological approaches which may more accurately reflect the difference between hospice and conventional care as experienced by patients and families. Finally in our compulsion to measure the worth of a smile, let us not set the value too low.

Endorsement of Responsive Evaluation

In an address "Planning and Evaluation for Service Improvement," H. G. Rogers, Deputy Minister, Revenue Canada, Taxation Branch, makes statements and takes positions that would concur with those of Balfour Mount and John Scott. Rogers is an important spokesman because as a previous Comptroller General and as Deputy Minister, Revenue Canada, he has been given a mandate to improve financial management practices and controls through the Federal public service. Rogers (1984:1) states:

> One of the responsibilities of my office was and still is to see that Federal departments and agencies evaluate periodically their programs in order to provide more and better information for decision-making. I look upon program evaluation as a vital part of the formal review and monitoring mechanisms which are essential for good management, particularly in an environment of expenditure restraint.

In speaking about the difficulties of evaluating social programs, Rogers raises several issues and suggests ways of dealing with these issues. Rogers' (1984:17-19,22) concerns and suggestions are presented below in point form.

> 1. It is generally recognized that it is difficult to evaluate social programs in a scientifically rigorous manner . . .
>
> 2. Social programs are complex undertakings which often deal with intangibles—attitudes, feelings and emotions. Their objectives are frequently stated in vague terms and sometimes for good reasons. Acceptance of many social programs may depend on different groups perceiving the objectives of the program to be different. In other cases, very little may be known about how to produce a social service effectively. Accordingly, it is difficult to develop agreement on what measures represent correctly the stated objectives or desired outcomes of a social program.
>
>   Even in a tangible area such as health, it is difficult to measure in a quantifiable and generally acceptable manner, the appropriateness of the level of medical care that is provided to a specific target group [emphasis in the original document] . . .

> 3. The appropriateness of medical care services can be assessed qualitatively however . . .
>
> 4. Obviously the scientific experimentation is seldom feasible for practical and ethical reasons . . . .
>
> 5. A crucial feature of the Federal approach which flows from the managerial use of program evaluation is the emphasis placed on the _relevance_, _reliability_, _objectivity_ and _timeliness_ of the evaluation findings rather than their _scientific validity_ [emphasis in the original].

The state of the art in hospice care is, as previously cited, thought to be outside the researchers' capabilities to quantify, measure and evaluate in the customary way.

Again, according to Mount and Scott (1983:735), "The tool that will measure the impact of hospice care may have to reflect 'meaning of life' and 'sense of personhood.'"

Purpose of the Study

Toward Responsive Evaluation of Hospice Care

It is part of the administrator's role in human service organizations to be responsive to client needs and to plan and evaluate programs to meet those needs. It is the author's contention that the evaluation method used to 'measure' the value of services provided by hospice and indeed any other human service organization must, as Rogers (1984) claims, place emphasis on _relevance_, _reliability_, _objectivity_ and _timeliness_. The model used to guide the evaluation process must move beyond the industrial, technical mode of measurement by production and performance if the essence and purpose of health care are to be captured.

The Research Goal

The purpose of hospice and other health care programs is to be responsive to the client, the patient and the family who are, for the time, in need of services the program was designed to offer. The purpose of this study is to focus on one small but essential piece of the hospice network of caregiving; the experience of home care for the dying as seen from the primary family caregiver's perspective (see Figure 2). The data and the findings that develop from the inquiry will, it is hoped, not only reflect the meaning of the family caregiving experience but will also be seen as useful base line data by health care administrators who plan and evaluate hospice care.

It is possible that the findings and particularly the evaluation model and assessment framework developed in this study may prove useful beyond the domain of hospice or palliative care for the terminally ill.

Focus of the Study

The primary focus of the study is on one aspect of the hospice way of caring for the dying. To further elucidate the domain, Figure 2 depicts the way that the

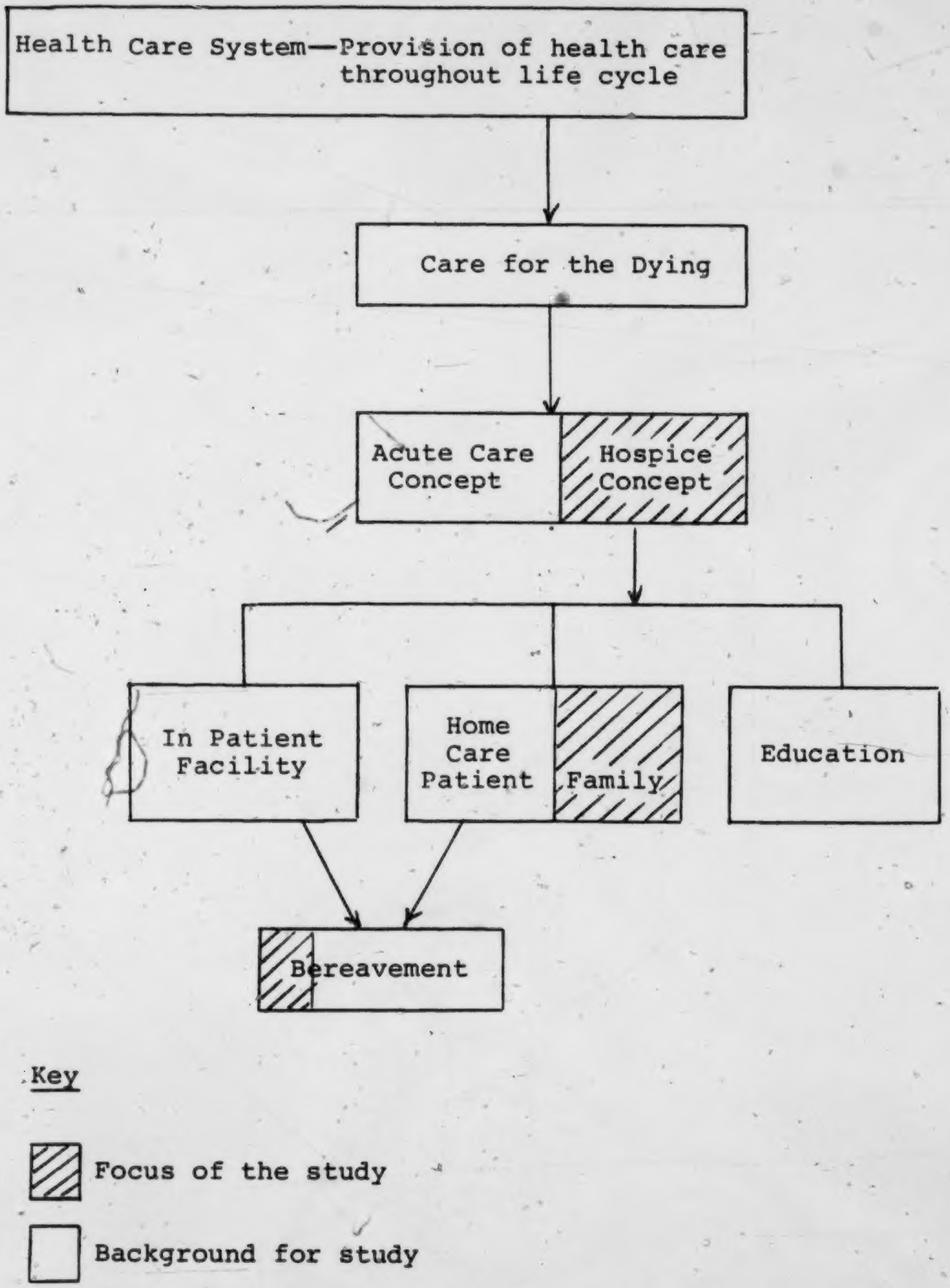
Health Care System—Provision of health care throughout life cycle
Care for the Dying
Acute Care Concept
Hospice Concept
In Patient Facility
Home Care Patient
Family
Education
Bereavement
Key
▨ Focus of the study
☐ Background for study

Figure 2

Depiction of Background and Focus of Study hospice concept of care may be thought to fit into the health care system.

The Significance of the Study to Human Service Organizations

The Importance to Clinicians and Administrators

Hospital personnel. Family centered health care is becoming an increasingly important aspect of practice. Discharge planning is an essential component of hospital care. Time, however, frequently constrains the practitioner from being able to sit and listen to the story, from entering into the subjective experience of the family member. Yet much of home care is planned around that key person, the primary family caregiver.

Including the family as a member of the unit of care is a relatively new idea. Davidson (1979), Forsythe (1980) and the National (U.S.) Hospice Organization Standards cited in Martin (1980:17) all underscore the need to consider the family as a central part of the treatment team although Wald et al. (1980:175) suggest that family participation will be a "challenge to the perception of family as visitors only." Family, particularly in hospice care, is essential, not peripheral to the patient care plan. Elaboration of this concept was undertaken by the author in Comprehensive Care for the Dying: An Organizational Model (McHutchion, 1980).

A relatively new aspect of providing home care for the dying was noted by Craven and Wald (1975), Agich (1978), Schecter (1980) and Martin (1981). Families are inexperienced with dying and death. On the one hand, if the patient wants to come home to die, the family members want to do as the patient wishes but they have very real fears about their abilities to cope with the strain of providing physical care to the patient up to and at death. Most people in our society have, in fact, not witnessed the dying process unless it has been muted by film or hospital routine. Croushore (1973) describes this fear well in her article "It's hard to sit with death."

Home care personnel. Family centered care has been the mandate of public health and home care professionals for many decades (Cunningham, 1976). However, family concerns have never been more crucial than at present with the increased emphasis on home care, particularly palliative home care for the dying.

Government activity, for example, is increasing in Alberta. A private member's bill endorsing palliative care has been brought to legislators' attention on two separate occasions (May 24, 1983 and March 22, 1984). An as yet unapproved Policy Paper: Palliative Care Services (1982) has been issued to professionals in the field from the Department of Alberta Hospitals and Medical Care. Evaluation is an essential component of the various models of palliative care recommended in the Policy Paper. Program funding, in fact, will not be forthcoming unless a plan for evaluation is submitted with funding requests.

Hard evidence of recent government interest is the partial financial support of the Palliative Care Unit at Edmonton General Hospital and the infusion of one million dollars for home care into the Alberta health care system (Alberta Hansard, March 29, 1984:213).

The health care delivery system is become impossibly expensive in these days of increased hospital costs and reduced financial resources. Home care for the dying may become less an option and more of a necessity if hospital costs continue to soar. Accountability and proof of value received for dollar spent is increasingly being required from professionals in human service organizations. Health care administrators will be required to meet the challenge to prove that programs are in fact viable.

For reasons other than economic, many government officials and lay and professional caregivers believe that the provision of home care support is an integral part of hospital service. British, American and Canadian physicians and nurses such as Simpson (1976), Schecter (1980), Dobihal (1980), Matthews (1980), Putnam et al. (1980) and Scott (1981) have all written at length about the need for providing the option of home care for the dying.

The Canadian Guidelines on Palliative Care (1981:3) support the need for a home care program as evidenced by the following statement:

> Often care at home is the plan chosen by the patient and the family. For most persons a large part of the "care" phase of their illness is spent at home and sometimes it is the patient's wish to die at home.

Further evidence of the interest in Alberta for home care for the dying is the following quotation from the proposed Policy Paper: Palliative Care Services, Alberta Hospitals and Medical Care (1982:27):

> As one of the goals of palliative care is to keep the patient in the home and as functional in society for as long as possible, a palliative home care program is considered essential to any overall program.

Squires (1981) sums up the beliefs expressed by many health care professionals by stating that home care is the primary objective of all models of hospice care. According to Squires (1981:22) "Our whole thrust is to keep people at home."

It appears that home care for the dying may become a probability for most families if the trend continues. The evidence cited is a mandate for practitioners and administrators to seek understanding of the experience.

Agich (1978), Bloom and Kissick (1980), Schecter (1980) and Ames (1981) in articles directed to administrators and planners emphasize the need for listening to patients and families who are to be the recipients of the care. For example, Bloom and Kissick (1980:563) in an ~~article on cost~~ effectiveness of home and hospital care state that information volunteered by families seems important, "perhaps more important than the documented large cost differences." Schechter (1980:65), publisher and editor of Hospitals, chaired a round table discussion of experts in the field of hospice care on accreditation of programs. He states:

> There are certainly two elements in how systems are perceived. One is within the professional system; another is how potential patients view the system. One of the key questions is to find out what the community needs and wants and whether these needs and wants are being met. To me that's a higher standard than those developed by a regulatory body.

On site information gleaned from listening to the subjective experiences of being the key caregiver, the family member "on-duty" twenty four hours a day, is of significant assistance to clinicians and administrators charged with providing palliative care for the dying.

Multidisciplinary health team personnel. Hospice care is provided by physicians, nurses, social workers, psychologists, physio and occupational therapists, pastoral care workers and volunteers (Cassileth and Donovan, 1982). Because the current study is concerned with the family perspective, the results are likely to be of interest to caregivers from all disciplines that acknowledge the value of the family as part of the unit of care. As Dobihol (1980:1449) notes, "in providing care, listening is always the key word. What the family wants and doesn't want is important as a beginning step, not what we, the staff, think they should need or want."

The Importance to Educators

Hospital roles and routines give professional caregivers some sense of order in working with dying patients. It is difficult for caregivers within the hospital setting to relinquish those defined roles and specified routines in the transition from an acute care approach to terminal care to a palliative/hospice approach.

Home care brings with it the possibility of professional autonomy which appeals to many professional caregivers. However, the security of the "hospital walls" can be missed particularly during a difficult death. Caregivers may find themselves unprepared for the freedom and concomitant responsibility that are inherent in community care.

Kübler-Ross (1974, 1975), Shephard (1976), Mandel (1980), Schecter (1980) and Scott (1981) emphasize the need for including palliative/hospice care concepts in educational programs for health care givers. There is in Canada and the United States a demand for workshops and seminars about care for the dying and their families from many hospital and home care nursing groups. It is timely for educators to consider including curriculum content based on patients and family experiences in their basic programs so that professional caregivers will be better able to work with dying patients and families.

The Importance to the Patient and Family

This study is timely in another sense. Recent field experience has demonstrated that gaps in service exist particularly in home care for dying patients and their families. The initial impetus for this study came, in fact, from field experience. Patients and families are either unaware of community and institutional services or find it difficult to move between health care and home settings. The family suffers during and after the death of the patient but are reluctant or unable to ask for help perhaps because they are not familiar with the changing health care system. Family members who take the patient home to die are presently being asked to provide many of the special services that a multidisciplinary health care team would provide in hospital settings.

The results of this inquiry have been written in a way that can be understood by lay and professional providers of health care service. Increased awareness among lay persons and professional caregivers will, it is hoped, result in more informed, responsive care for the dying and their families.

Broadening the Context: Applications of the Findings

Based on Dr. Cecily Saunders' concept of hospice care a natural extension of the current research would be a comparison of the findings on terminal care to the family caregiving experience for:

1. chronically ill patients who have longer life spans than the palliative care patients in the study;
2. elderly, dependent parents;
3. physically or emotionally handicapped persons.

For example, in a current issue of Alberta Psychology, Professors Keating and Gilewich (1985:17) write about the burden of family caring for the person suffering from "senile dementia of the Alzheimer's type (SDAT)." The authors (1985:17) report that:

> Both personal resources of caregivers and the amount of informal and formal support they receive have been recognized as potentially important in reducing both impact and burden. The caregiver who can afford to hire a live-in helper might be able to continue with community involvement. The availability of respite care might mean that a family can have a vacation. If resources are high, impact might be relatively low. For example, some family members act more as care managers than as direct care providers by mobilizing community resources to care for SDAT members.

Keating and Gilewich, believing the family caregiving experience to be important, will in fact do further inquiry into the related experience of caregiving for a person with Alzheimer's related disease.

To further tie the findings of the study to other areas of health care and to further illustrate the beliefs among professionals about the provision of home care by family members, the following excerpts from a current study are included. The quotations are taken from Health: A Need for Redirection, a report published by the prestigious Task Force on the Allocation of Health Care Resources. The Task Force was sponsored by the Canadian Medical Association and they published their broadly researched findings in 1984. The theme of the report is the need to "de-institutionalize" our health care system.

> Re: Palliative Care. Some dying patients may prefer to be in a hospital, but most would rather remain at home surrounded by their friends and family, and indeed, should be able to do so. But we do not now have the community resources to provide the appropriate care to make this possible. (p. 24)

> Re: The Elderly. If we continue to put old people in institutions at the rate we do now, the costs will not only be prohibitive, we will perpetuate the callous practice of warehousing the elderly. Old people do not want to live in institutions, even in the best of them. Governments are worried about the additional stress on budgets. (p. 18)

The Task Force recommends that the following care services be made more readily available: Home Care Nursing, Meals on Wheels, Respite Care, Volunteer Visitors, Homemakers, Handyman Programs, Drop-in Centres, Transportation Services, Day Hospitals, Mobile Hospitals.

Although the Task Force report is a document that reflects the sensitivity and responsiveness of the Task

Force members, the key participant in the home care scenario, the primary family caregiver, is for the most part taken as a 'given.' (As an interesting and pertinent aside, in the initial phase of this study it was found that some of the family members felt overwhelmed by the sheer amount and numbers of services provided by well-intentioned helpers.) The Task Force document reflects the very logical professional opinion found in the field and in the previously cited Keating and Kilewich article. If a variety of services to the terminally ill patient and family could be provided, it is thought that home care would be much improved.

The findings of the current study are likely to be pertinent to various dimensions of home care and institutional care as the family experiences reported help to clarify not only "what helps" but also "how much help" is required. However, keeping in mind Greenfield's (1980) and Calkins' (1986) thesis that organizations are complex, and that they are "limited and defined by human action" (Greenfield, 1980:27), the ultimate goal is that the reader may reflect on the findings and be "influenced" to reconsider his or her own attitude and action toward care for the dying. Through reflection on the complexity of the domain of the dying the caregiver and the educator may be better prepared to develop uniquely tailored services and curricula that are responsive to the needs and wishes of the patient and family.

The Nature of the Study

Choosing a Method of Inquiry

The preliminary readings and reflections that led to the delineation of the research question led to the further question of how to go about the inquiry. Opening the question of research process also opened the Pandora's box of qualitative vs. quantitative ways and means of analyzing information that in turn would be judged useful in the process of developing social science theory. Should this study use the process of discovery or validation?

Lindeman (1986) sets the premise upon which the selection of research process was made for this study. Lindeman (1986:31) states:

> It is my premise that the nature of the questions and the phenomena to be studied mandate the method for study as opposed to the method being the determinate. It is also my thesis that the generation of knowledge involves both discovery and validation and that the processes are related but distinguishable phases that vary considerably.

It is the researcher's contention that the nature of the question itself precludes the use of the questionnaire and therefore forfeits the strength associated with data supplied by a large but randomly selected sample of respondents. Lindeman's (1986) statement about choice of research method made to an audience of nurses has relevance to this study. Lindeman (1986:31) warns:

> Premature preoccupation with formal process may be handicapping to the development of a nursing knowledge system if indeed knowledge of some particular class of human perceptions and misperceptions, human feelings, human sensations, and human responses are among the realities that nurses observe and attempt to understand in a nursing context. . . . there is a disjunction between nursing's subject matter of human care and the methodologies nurses have adopted from the traditional natural sciences and medicine.

The controversial and unfinished state of the art of inquiry into the hospice experience was another determining factor for deciding to follow the route of discovery rather than validation of existing hypotheses about the hospice concept. The chosen method of inquiry and analysis of data is further elaborated in Chapter 3. The problem that remains, however, is to sort out the conflicting arguments about the "fundamental image" of the "subject matter" (Ritzer, 1975:157). The research paradigm for this study needs to be reflected upon, described and explicated.

The Paradigm

The Definition of Paradigm

According to Ritzer (1975:157):

> A paradigm is a fundamental image of the subject matter within a science. It serves to define what should be studied, what questions should be asked, how they should be asked, and what rules should be followed in interpreting the answer obtained. The paradigm is the broadest unit of consensus within a science and serves to differentiate one scientific community (or sub-community) from another. It subsumes, defines and interrelates the exemplars, theories, methods and instruments that exist within it.

According to Scott (1981:122), a paradigm provides a framework of assumptions and axioms within which "normal science" can proceed. Critical concepts are identified, and essential relations specified: it provides a map of the scientific terrain to be explored.

The Issues in Paradigm Selection

Much time, effort and ink have been used by scholars in the various disciplines of the social sciences to demonstrate the strength of a particular way of viewing and managing the subject matter within the pertinent discipline's boundaries. Writings in the disciplines of education, nursing, psychology and anthropology point to a common difficulty that cuts across individual disciplines and that may be described as a confrontation between the two cultures of the physical or natural sciences and the humanities. According to Prigogine and Stengers (1984:xxix), "Traditionally science has dealt with universals, humanities with particulars." The social sciences which attempt to deal scientifically with humanity are particularly vulnerable to the current unease that permeates scholarly endeavours. Prigogine and Stengers (1984:308) describe the foment as follows:

> Instead of working in unison, the members of the [scholarly] community begin to ask "basic" questions and challenge the legitimacy of their methods. The group, which by training was homogeneous, now diversifies. Different points of view, cultural experiences, and philosophic convictions are now expressed and often play a

> decisive role in the discovery of a new paradigm. The emergence of the new paradigm further increases the vehemence of the debate. The rival paradigms are put to the test until the academic world determines the victor.

Greenfield (1980), education, Hockey (1986), nursing, Prigogine and Stengers (1984), psychology, and Sass (1986), anthropology, are examples of authors who have recently written about the struggle with paradigm and methodology that is currently in evidence within and between disciplines.

Disagreement among scholars holding opposing views concerning the "right" way to inquire into any phenomenon under study tends to have its roots in philosophy as well as traditional science. The underlying philosophical stances taken by proponents for each "culture" may be described in a series of x vs. y elements of concern and divisiveness.

	Stance X		Stance Y
Re Knowledge:	logical positivism	vs.	anti-positivism
Re Choice:	determinism	vs.	free will
Re Research Methods/ Perspectives:	classical objective	vs.	subjective perspective
	simple	vs.	complex
	hierarchy	vs.	heterarchy
	mechanical	vs.	holographic
	linear causality	vs.	mutual causality
	reductionist	vs.	inductive
	nomothetic	vs.	idiographic

As difficult and frustrating as it is to sort through the literature from the various disciplines, as Prigogine and Stangers (1984:302) suggest, "Exploring the implications and coherence of these fundamental concepts may be risky, but it can be very fruitful in the dialogue between science and philosophy."

Reflection on Paradigm

There is a subtle difference between selecting a paradigm to fit the nature of inquiry and the alternative method of fitting the inquiry into a particular paradigm. The author has chosen the first option. There are several good reasons for deliberating about paradigm selection at this juncture of the study. The paradigm selection process helps to clarify the thinking of the researcher as it tends to illuminate some of the darker recesses of the mind. Beliefs, then underlying assumptions, are called into question as the elements of paradigm are considered for appropriateness not only to the researcher's own vested interests in the disciplines of education, nursing, psychology and anthropology but also to the appropriateness of the paradigm to the domain of the inquiry.

Dr. Lisbeth Hockey (1986) in the keynote address to the International Nursing Research Conference in Edmonton in May 1986 raises some interesting points that are pertinent to this deliberation. Hockey suggests that there may be several pragmatic factors that influence and limit the choice of paradigm and method of inquiry. Hockey (1986:21) notes:

> Thus, whilst it might be creative, indeed logical, to search for the most appropriate research approach for the pursuit of the idea, the specific faction represented by the University Department or the individual academician within it, tends to have priority. Although this is of course a generalisation it is worthy of thought.

Hockey (1986:21) makes another intriguing point in speaking of the "well guarded empires of research."

> Sometimes, the reluctance to move across even if only to test the water, is due to uncertainty and even fear. Both uncertainty and fear may be related to lack of confidence in one's own knowledge and competence or to apprehension about the likely reception in a territory, not conventionally one's own.

Hockey makes one other supportive statement that encourages the researcher to jump the boundaries of one's own particular discipline(s) and refuse the reductionism of Ritzer's definition of paradigm. Hockey (1986:23), interestingly enough in the context of promoting evaluation as a necessary and timely exercise for nurse researchers, offers the following advice that is applicable to disciplines other than nursing:

> Meaningful participation in such [evaluation] research requires a new vision and new frontiers. It demands a greater willingness to enter into a working relationship with other disciplines within and outside our narrow specialty, without loss of the uniqueness of nursing. Uniqueness does not mean isolationism. The more nursing attempts to keep itself to itself the less opportunity it has to demonstrate its unique and complex knowledge base. Nurse researchers must gain sufficient

> self-confidence to develop new and creative relationships with other disciplines, if only to explore the utility of their approaches to the study of nursing and to attempt an appropriate unique mix of research approaches to match that of nursing itself. If we accept holistic nursing as a commitment, our research approach must reflect it.

Citing Hermeren (1985), Hockey (1986:24), again in speaking of research toward evaluation, states:

> Good evaluation cannot be limited to the study of only one kind of effects, be they economic or psychological or whatever. When the various kinds of effect are related to each other we are faced with the problems and promises of interdisciplinary research.

Scott (1981) is given the last word. Scott (1981:122) suggests that ". . . in some respects competing paradigms are incommensurate, and the differences between them cannot be completely resolved by scientific evidence or argumentation." Scott (1981:122) makes the point that the social sciences are in a pre-paradigm phase of development still "waiting for our Copernicus and our Newton." Nevertheless, it may be possible to bridge the gap between science and philosophy, and between the universal and the particular and to find elements of a paradigm that are interdisciplinary in scope.

Following Scott's (1981) lead, this study uses a number of perspectives to map the territory of the inquiry. The paradigm that is described in Lindeman (1986) has the potential to link the domains of research, theory and practice and is presented in Figure 3.

Mapping the Territory: The Perspectives Approach

Again, following Scott's (1981) definition of paradigm, the paradigm described by Lindeman (1986), includes basic assumptions, critical concepts and essential relations. Elements of the Lindeman health care paradigm are presented in point form.

1. The traditional bio-medical, (natural science) paradigm is inadequate to meet the requirements of current and emerging health care situations.

2. The goal of science is to improve the quality of life.

3. Science is both pragmatic and humanitarian.

4. Practice and reflections on practice are the major sources of knowledge to both the practitioner and the researcher.

5. There has been a shift of the focus of health care from pure "care" to helping people help themselves.

6. Generating knowledge is an interactive, iterative process and may involve discovery and validation, two related but distinguishable processes.

7. The place to begin the inquiry is with the provider-client component depicted as an interaction and cast within a specific context.

To summarize, the key concept in Lindeman's version of the health care paradigm is client-centered inquiry for the purpose of establishing links between research, theory and practice. The discovery process may be thought of as modelled in Figure 3.

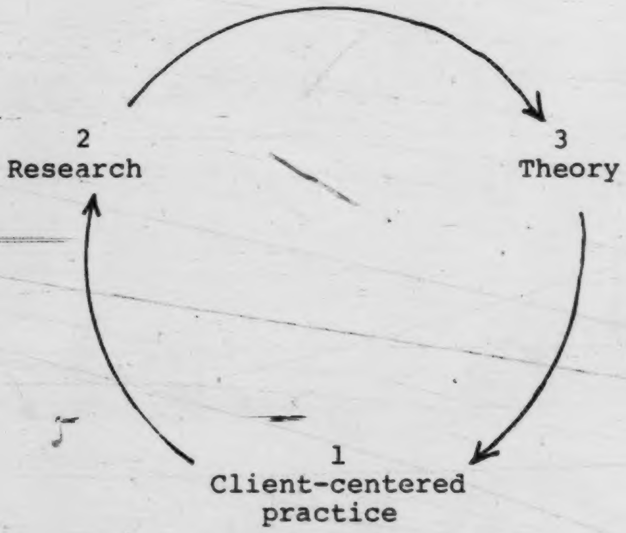

Figure 3

The Research Cycle

Broadening the Health Care Paradigm: Other Perspectives

Geertz, a well known anthropologist, would agree with Lindeman's contentions. Geertz argues that "human action cannot be properly understood, or even described, if one takes the objectivist's point of view generally associated with the natural sciences." "—[Geertz sees] . . . his field's true mission not as the behavioral observation of other societies but as the comprehension of their point-of-view" (Sass, 1986:52).

Lindeman's and Geertz's perspectives on paradigm can be linked to a very specific part of Max Weber's work, i.e., his analysis of social action. Weber (as cited in Ritzer, 1975:162) claims that ". . . social scientists must involve themselves with interactants using a form of sympathetic introspection in order to understand the meaning contexts that serve as the impetus to action."

Ritzer (1975:161) further describes the approach: "Social definitionists tend to be interested in the mental process as well as the resulting action and interaction." Man is not controlled by norms, values, social agencies nor by reinforcement but is an "active creator of his own reality." Weber, it appears, would have supported the shift of focus of health care described by Lindeman. Pure care is no longer the mandate of the health care professional. The trend is toward helping the patient help himself.

It would be inappropriate to leave the discussion of the 'health' care paradigm without making the further claim that health is not yet well understood but is not limited to 'absence of disease.' Health is a concept that is difficult to define. According to Florence Nightingale "We know nothing of the principle of health, the positive of which pathology is the negative, except from observation and experience. And nothing but observation and experience will teach us the way to bring back the state of health" (Nightingale, 1860:133). The search for definition continues.

As Prigogine and Stengers (1984:299) wrote: Knowledge is "both objective and participatory." ". . . our feeling of intellectual security has been shattered. We can now appreciate in a non-polemical fashion the relationship between science and philosophy." These authors claim that Galileo's mechanistic question "how does it work" and the Aristotilean's philosophical response "but why?" are not incompatible questions for the researcher to query (Prigogine and Stengers, 1984:40). To put the matter back into the educational administrator's perspective, "The root problems of organizations thus dissolve into questions about what people do, why they do it, and whether what they do is right" (Greenfield, 1980:27).

In conclusion, the inquiry that is the purpose of this study lends itself to an inductive and descriptive method of research. The client-centered (emic) perspective is consistent with the health care paradigm as elucidated by Lindeman, Geertz, Weber and Nightingale. The end result is the development of a conceptual framework based on hypotheses that are true to the data, the stories and the observations heard and seen by the researcher over a protracted period in the field. It is hoped that the hypotheses will serve as an "impetus to action."

Paradigm into Practice

Tentative Claims for the Study

Hypotheses are elements of theory. No unrealistic claims are made for the level of theory development reached for in this study. Silver (1983:4), however, defines theory in a way that allows the researcher to consider theory development as one of the appropriate goals for this inquiry. According to Silver, theory is:

> A unique way of perceiving reality
>
> An expression of someone's profound insight into an aspect of nature
>
> A thought system that reaches beyond superficial experience to reveal a deeper dynamic than people usually perceive
>
> A fresh and different perception of an aspect of the world we inhabit.

Silver (1983:4) goes on to say: "This [preceding] interpretation of the nature of theory does not sound very scientific. More formal definitions are dry, however, robbing theory of its beauty, its emotional significance, its importance in everyday life."

If clarification of one's paradigm and research methods is enhanced by contrast and stating what the paradigm or method would not include, Fiegl's definition of theory would be a useful addition to the discussion:

"I propose to define a 'theory' as a set of assumptions from which can be derived by purely logico-mathematical procedures a larger set of empirical laws" (Griffiths, 1983:203). Theory development in this study is aligned with Silver's definition.

Placing the Conceptual Framework

According to Evelyn Adams (1984:vii)

> A conceptual model for nursing is a conception of what nursing should be . . . Broader than a theory, a conceptual model is a pre-theoretic base. Because it specifies nursing's particular focus of inquiry, a conceptual model may lead the nurse researcher to develop theories which would prove useful not only to nurses but to other health professionals as well.

Adams (1984:90), in writing about the composition of a conceptual model, claims that the model needs to be based on principles and values and contain the elements of goals, the ideal and the real; the client as the basis of the professional's activity and the problem to be solved is to be as reported by the client (translated from the French text).

The hospice concept of care for the dying, the client-centered approach to evaluation and the research goal of theory development described in this document meet Adams' criteria. The health care paradigm, the method of research, i.e., the inquiry into the experience of care giving from the client's perspective are consistent with Adams' advice. The definition for conceptual model from Theoretical Pluralism in Nursing Science, just cited, is from a collection of papers presented at the 1982 Learned Societies meetings of the Canadian Association of University Schools of Nursing. Although the focus of the definition is nursing, the substance of the definition is transferable to the present study.

Another author who speaks to the problem of the development and placement of the conceptual frameworks is Paula Silver (1983) in Educational Administration: Theoretical Perspectives on Practice and Research. Silver (1983:13) in the figure replicated below, demonstrates the ladder of abstraction that conceptualizes the placement of a conceptual framework in the traditional mode of research.

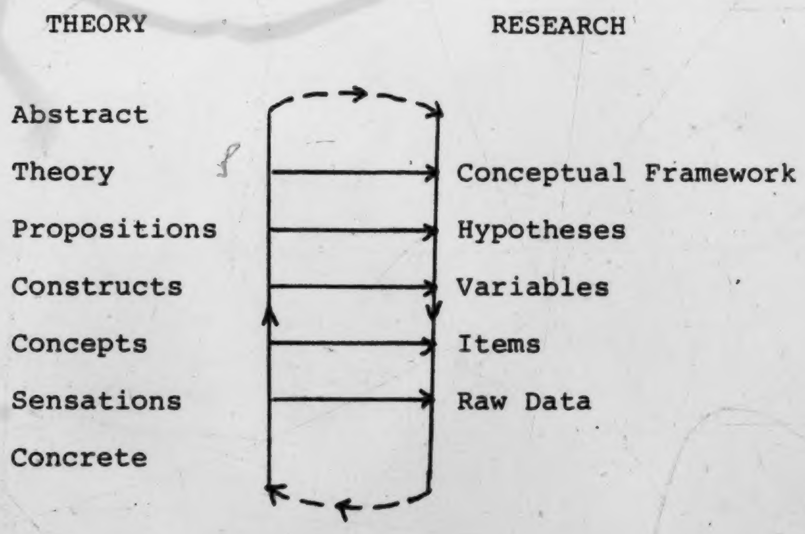
THEORY
RESEARCH
Abstract
Theory
Conceptual Framework
Propositions
Hypotheses
Constructs
Variables
Concepts
Items
Sensations
Raw Data
Concrete

Figure 4

Theory and Research in Relation to a Ladder of Abstraction

Silver's (1983:10) paragraph on placement of this conceptual framework in a deductive inquiry is as follows:

> A theory has been defined as a set of logically interrelated propositions. These propositions are generalizations that pertain to an infinitely broad array of particular situations or events. Since a study must confine itself to a sample of particulars, the context in which those particulars are being viewed must be explained at the outset. In other words, the theory being used as the basis for selecting the events to be studied must be described and linked logically to the particular problem being investigated. The theory serves to clarify the perspective or conceptual framework to be used as the foundation of the empirical study.

In contrast, the Ladder of Abstraction that best described the current study on entry to the field may be depicted in Figure 5.

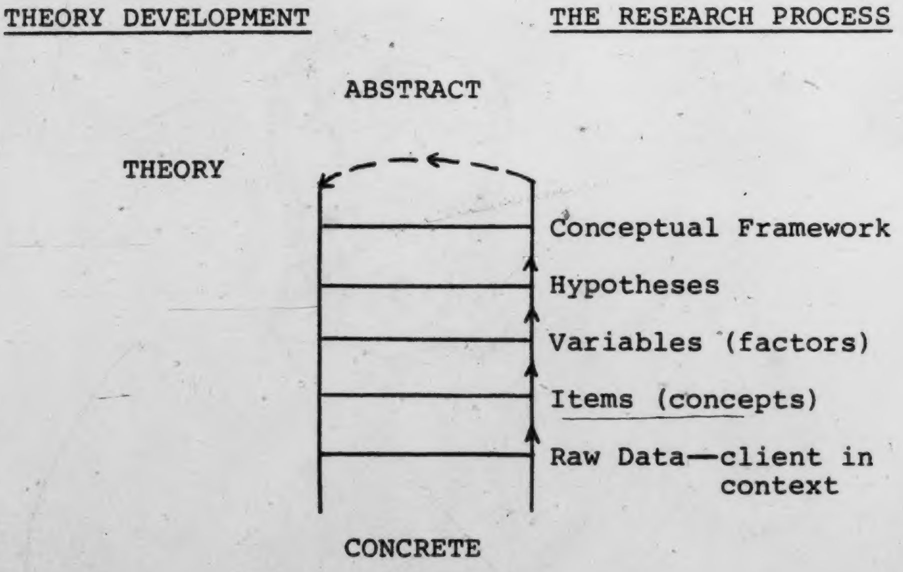
THEORY DEVELOPMENT
THE RESEARCH PROCESS
ABSTRACT
THEORY
Conceptual Framework
Hypotheses
Variables (factors)
Items (concepts)
Raw Data—client in context
CONCRETE

Figure 5

Research Process in Relation to Theory Development

Cronbach (1975:126) closes the deliberation on paradigm selection with the following statement that reflects the 'point . . . counterpoint' pacing of this thesis:

> Social scientists are rightly proud of the discipline we draw from the natural side of our ancestry. Scientific discipline is what we uniquely add to the time-honored ways of studying man. Too narrow an identification with science, however has fixed our eyes upon an inappropriate goal . . . The special task of the social scientist in each generation is to pin down the contemporary facts. Beyond that, he shares with the humanistic scholar and the artist in the effort to gain insight into contemporary relationships, and to realign the culture's view of man with present realities. To know man as he is is no mean aspiration.

Organization of the Thesis

The first chapter has been an extensive exploration of background materials related to the subject context and research process. The inclusion of selected parts of the reflective process undertaken by the author continues throughout the thesis. Reflection on content and process is necessary on two counts. The hospice philosophy encourages anyone who associates with 'the dying' to become aware of his or her own attitude toward dying and death. The chosen research process also requires the researcher to capture thoughts, feelings and insights by doing spontaneous and/or reflective 'memo'-ing (Glaser, 1978). All materials are considered data.

The second chapter reports a preliminary review of the literature that is consistent with the discovery method of inquiry (Glaser and Strauss, 1965). In Chapter 3 the research method is further developed. Chapter 4 presents the participants and their experiences with caregiving to the dying. In Chapter 5 the findings are organized into hypotheses and an evaluation framework presented for the reader's consideration.

Chapter 2

REVIEW OF THE LITEPATURE

Introduction

Chapter 2 presents a preliminary review of the literature on attitudes and issues concerning dying and caring for the dying for the purpose of providing a context and domain for the inquiry (Diers, 1979). Following the advice given by Glaser (1978) and Bogdan and Biklen (1982), and because of the subjective nature of the topic, scholarly professional journals and the 'paper-back' press are considered worthy sources of information. A portion of the material cited in the chapter was gathered and reported in the author's Master's project, Comprehensive Care for the Dying: An Organizational Model (McHutchion, 1980).

The review is organized using a perspectives approach. Society's perspective on death, the institutional perspective on care and current perspectives on research into the dying experience are included. Diers (1979), who recommends the 'themes' approach to organizing subject matter, also encourages authors to write the literature review in a way that will stimulate thinking and build toward the research question. Statements that reflect the controversy in the literature are therefore included and the chapter ends with an identified domain for the inquiry.

The preliminary review of the literature was not for the traditional purpose of finding existing theories to guide the study. In keeping with the discovery method of research, a further review of the literature related to developing themes is presented in the final chapter (Glaser, 1978; Bogdan and Biklen, 1982; Hutchinson, 1986).

The Societal Perspective on Death

"From the first dawn of consciousness, death has been a mystery to mankind" (Adler, 1976). Yet, according to Feifel (1959), there was in earlier civilizations, a sense of death having meaning and an important place in the natural order. In two of the great living religions, Christianity and Buddhism, the meaning of existence, of life, is consummated in its end. However, man, particularly in western society, began to lose his belief in God and therefore his belief in immortality and to a great extent his belief in meaning in life and death.

Western Society's Attitude Toward Death

Anthropologists, Huntington and Metcalf (1979:203) trace the changes in attitude toward death:

> Since the fifteenth century, there has been in the West a continuous tradition of literature on how to die . . . The earlier volumes urge that the sinner "look on death" in order to wake the fires of conscience; the latest writers advise a sidelong glance in order to avoid psychological maladjustment.

Late twentieth century man has vacillated between cool detachment and extremes of sentimentality in elaborate attempts to "bury death" (Feifel, 1959; Lamers, 1982; Gardner, 1983). Feifel (1959, xii) writes that modern man has "tended to run and hide, and seek refuge in group and actuarial statistics." It is thought that "the life of the individual should rise in an arc through brassy youth to fruitful middle years, and then decline gently toward a death that is acceptable as well as inevitable" (Huntington and Metcalf, 1979:205).

Jessica Mitford (1963) and others have decried the "Forest Lawn Memorial Park" syndrome in which death is buried in euphemism. There have been changes in public attitudes since 1963 when Mitford shocked the reader with her cynicism toward North American death rites and rituals. However, the following description by Huntington and Metcalf (1979:194,195) of "passing on" may in the late 1980's still have a ring of truth:

> The majority of deaths now occur in hospitals, where the fiction of probable recovery is often maintained until a person is near the point of death. The corpse is then promptly removed without the aid of the bereaved, who see it again under very special circumstances, after it has been primped up to appear as if asleep. Coffins are selected for their superior padding, as if

> comfort mattered to the corpse. We speak of the deceased as having "passed on"; we describe the premises of the death specialist with the cozy-sounding terms "funeral parlor" or "funeral home"; we comment on how "well" the embalmed corpse looks lying in the "slumber room". . . .

In both extremes, detachment and sentimentality, ". . . we attempt to conceal what we can neither face nor escape" (Lifton et al., 1974:18).

There have been other changes in western society, particularly in North America in the last fifty years, in the way of living and dying. Dr. Balfour Mount, quoted in English and Wilson (1978:9), reflects on the past:

> At the turn of the century we were an agrarian society. Birth, life and death were shared events. They occurred within the home environment and when grandpa fell off the hay mow, he was laid out in the front parlour. Neighbors and grandchildren came to pay their last respects. We perhaps tend to romanticize the "death with dignity" that followed, but in any event, it was shared death. Death was seen as a part of life. It happened naturally, every day, and was seen in the context of nature with its cycles of life and death. The high mortality rates associated with infancy, maternity and infectious and other diseases helped to increase this sense of familiarity with death. Death could hardly be ignored.

The Influence of Modern Medicine

Modern medical science has done much to influence society's changing attitude toward death. It appears that man is increasingly in control of his own life and death. The mortality rate has decreased. More diseases are curable and for those diseases that have no cure, life can be extended. Medical engineers have devised highly specialized machinery and pharmacologists have developed complex drugs that can be used to prolong living (or dying) to extraordinary lengths. In fact, according to Huntington and Metcalf (1979:204),

> . . . the place to begin looking for these [North American] attitudes [concerning death and dying] is not in the representations of organized religion, but in something more pervasive—medicine. [North] Americans have vast faith in medicine—a faith that is certainly in tune with the Enlightenment values of progress.

Bernard Lowen (1983:12) elaborates on medical progress:

> The growth of medical scientific insight during the past half a century has exceeded the accumulation of knowledge during all the proceeding millenia of recorded human history. An elegant, ever-burgeoning technology makes it possible to probe recesses of the body and decode the secrets of many pathological processes. The enormous medical accomplishments, the consistency of results, the reproducibility of findings, and the resolution of life-threatening disease all derive from the rigorous application of scientific methods and spur confidence in the biomedical model.

Dying. The increased sophistication of technology and expertise that may be used in the service of improving the quality of life (or merely in increasing the quantity), has added to the complexity of modern living and dying (Abdurrahman, 1974; Coffey, 1986). The moral dilemma of having to decide to discontinue curative treatment of the critically ill has necessitated a description of the terminal state. Although the decision to continue or discontinue curative treatment is at present left to the physician, usually in consultation with the patient and his family, there are, as yet, no hard and fast rules to follow in making that critical decision. For the purposes of this document, Veatch's (1976:3) definition is used:

> Dying is used here to refer to anyone with a specific, progressive, normally irreversible ailment which will eventually end in death and which has become so debilitating that it has seriously disrupted normal life patterns.

Death. Williamson, a general practitioner, writes about the physician's dilemma and frustration of dealing with death in this technological age in this way:

> I remember when cessation of heartbeat was an observation on which we simply pronounced the patient dead; now this is a medical syndrome known as cardiac arrest, . . . cessation of respiration is a symptom also implying death, which can now be corrected by an ingenious and devilishly efficient machine known as the mechanical respirator. (Quoted in Hendin, 1973:21)

Kastenbaum echoes Williamson. "There is simply no place for a human death when the dying person is regarded as a machine coming to a full stop" (quoted in Hendin, 1973:88). In hospital, the institutions in which most North Americans die, it is increasingly difficult to know where the machine leaves off and the person begins; to know where life has ended and death occurs.

Due to the present confusion surrounding the fact of death, defining death is not a simple task. Yet because of the present ethical and legal ramifications in this day of organ transplants and prolongation of life, it has become essential to have agreed-upon criteria for defining death. The criteria for death most frequently quoted in the literature are based on the decision of an ad hoc committee of the Harvard Medical School. Hendin (1973: 32) describes the criteria as follows:

> Clinical death occurs when spontaneous respiration and heartbeat irreversibly cease. The criteria are:
>
> 1. Unreceptivity and unresponsiveness
> 2. No movement or breathing
> 3. No reflexes
> 4. Flat encephalogram.

Because of the escalation of the use of technological means to fight death and to keep people clinically alive the question arises as to what is a timely death? Is there ever an appropriate time to die? The second half of the twentieth century appears to be the era in which ". . . life bases itself upon self-transcendence" (de Beavoir, 1977:414). In spite of an increasing interest in gerontology (Ragan, 1979; Troll, 1979; Rashkis, 1981), according to Mount (1986:14), "All of us, medical staff included, are raised in a youth-oriented culture that denies death as much as possible." Perpetual self-transcendence and prolonged maintenance of youthful strength are attractive notions, however, if these are considered to be life's only goals, mainstream society and medicine appear to be at odds with reality.

The Philosophical Response to Modern Medicine

Several writers in fact have defined or described what they consider to be a timely, appropriate death (National Hospice Organization, 1981, Appendix 1). Hinton (1967), who wrote *Dying*, a book highly regarded by other authors and speakers, has devoted a chapter to the description of natural, acceptable death. In a section entitled 'Timely Death' Hinton (1967:43) writes:

> To see death as entirely appropriate (an important part of much religious teaching) removes misgivings. It also has firm support from biology. . . . The biological necessity to die has influenced some of the psychological concepts of man's nature.

Hinton went on to quote philosophers such as Montaigne, Socrates, Plato, Spinoza and Epicurus who not only talked of the possibility of appropriate, acceptable death, but who also, in fact, demonstrated the validity of their philosophical beliefs by accepting and even affirming their own deaths. As Senaca commented, "death is sometimes a punishment, often a gift, and for many a favor" (Lowen, 1983:21).

Hinton (1967:49), presupposing an attitude of cynicism or disbelief on the part of the reader, goes on to say:

> It may seem that only an exceptional person could show such saint-like courage and calm as death approached, but the next chapter [in Hinton's book], concerning the way that ordinary folk die, will show that this is no rare virtue.

Weisman (quoted in Schneidman, 1973:25) further describes what he calls an appropriate death: ". . . a death which a person might choose for himself had he an option." He explains the characteristics of the concept further:

> [There is] continuity of significant relationships and consummation of prevailing wishes. [It is] appropriate to the individual's time of life, to his style of life, to his situation in life, to his mission (aspirations, goals, wishes) in life and it is appropriate to the significant others in his life.

Kübler-Ross (1969:120), in her first book, On Death and Dying, supports the possibility, even the probability of an appropriate death when people have had their needs met and have been given proper support from their environment. She describes her experience and her belief about the purpose of death:

> We have seen the majority of our patients die in the stage of acceptance, an existence without fear or despair.
>
> . . . Maybe at the end of our days, when we have worked and given, enjoyed ourselves and suffered, we are going back to the stage that we started out with and the circle of life is closed.

In this she echoes many other authors who could be quoted to support this hopeful, yet apparently realistic notion about the possibility of meeting death, appropriately, when the proper time arrives.

Understanding the Paradoxical Nature of Attitudes Toward Death

Timely, appropriate death is a hopeful sounding concept and yet the scholarly and popular literature reflect the ambivalence most members of Western society have toward the mystery of death. Balfour Mount, during a seminar in 1980, talked about the basis of the dark side of this ambivalence. He quoted Feifel's hypothesis and added to the explanation from his own experience. Feifel believes that our discomfort and ambivalence come from fear and he identifies seven fears that evolve essentially from loss of ego, identity and control, fear of the loss of self and all one values. They are:

1. The finality of death,
2. Fear of losing consciousness,
3. Fear of loneliness and separation,
4. Fear of the unknown "undiscovered country,"
5. Fear of punishment or mutilation,
6. Fear of what may happen to one's dependents,
7. Fear of failure.

Balfour Mount adds:

8. Fear of pain and other distressing physical symptoms,
9. Fear of becoming helpless and losing control.

Mount, in a recent seminar on Palliative Care (February 27, 1986), made the following comments about recent changes in our cultural attitudes toward death and our care for the dying:

> In recent years there has been a growing awareness of the psychological and emotional consequence of denying death and our culture reflects that too. The same media that have contributed to our denial of death as a reality, have taken up the theme. Movies such as "Terms of Endearment" and "All That Jazz" and television specials on dying cancer and AIDS victims encourage us to reassess our attitudes about death and our care of the dying.

Conclusion

The prospect of dying and death is difficult to face. La Rouchefoucald, a seventeenth century philosopher said: "Neither the sun nor death can be looked at with a steady eye." Attitudes toward death that prevail in our society were described in pendulum fashion that reflects our ambivalence yet need to understand and respond to the mystery of death.

There is much to be gained by acknowledging the fact that people (we) do indeed die. Denying death does not make the event less likely or, ultimately, less frightening. In fact, by facing the reality of dying and death and looking at the process from many possible perspectives, society may be able to plan institutions for the terminally ill patient with knowledge and sensitivity so that we may properly support the individual and family throughout the final stage of life.

The institutional perspective on care for the dying is described in the following section of this document.

The Institutional Perspective on Care for the Dying

The Development of Institutional Care

To give the necessary context for the critique of institutional care, a short overview of the development of the North American hospital is developed from Starr (1982) and Mauksch (1975).

According to Starr (1982:72) in "the early nineteenth century, there was little demand for the services of general hospitals in [North] America. Almost no one who had a choice sought hospital care." However, from "the beginning of the industrial era, changes in work and family structure probably created a growing disposition in favor of extra-familial care." Starr lists a number of influences that predisposed individuals to use hospital as the place to provide care for the sick and dying. Hospitals relieved the household of obligations that interfered with the market economy, segregated death and pain and provided the only source of care for an increased number of individuals without family, living alone in the city. Families were less able to provide care for the dying because work was done away from the place of residence. Modern urban families were small, isolated from extended family, had higher geographic mobility, less physical space and were less likely to have hired help. Physicians were less likely to visit the home as diagnostic equipment became more complex and ancillary office personnel were hired. Increased value was placed on the physician's time and it became possible and more efficient to see a number of patients quickly within the hospital.

Mauksch, quoted in Kübler-Ross (1975), sums up the reasons for the present status of the hospital in Western society. In summary form, his analysis is as follows: "Our differentiated, highly complex society endows occupants of social roles and institutions with mandates which denote their purpose, their function and their values. The hospital is a result of social expectations."

Although North America has a comparatively high standard of health care, health care organizations, particularly hospitals, have received criticism from within and outside the system.

The Prevailing Attitude Toward Health Care

Storch (1986:19), who has done extensive research on health care consumers' rights, states:

> One of the major concerns of consumers in health care is the tendency of caregivers to be mechanistic, or interested in only one body part or one body system at a time, as opposed to holistic, in which the total person is considered. Further the capacity of the patient is often inadvertently or deliberately ignored.

For example, it has been said that institutions are structured more to meet cure-oriented staff needs than the less clearly defined and more inclusive needs of the patients whom they are meant to serve (Hinton, 1967; Sarton, 1978; Cousins, 1983). If health care institutions have not met the holistic needs of the temporarily ill as critics imply then how well do dying patients fare in an institutional setting?

The Prevailing Institutional Attitude Toward Care for the Dying

The literature appears to support the notion that health care institutions reflect society's ambivalence toward those who have somehow failed to meet the unwritten challenge to be diagnosed, treated, cured and discharged. Strauss (1975) speaks about the loss of control experienced by the patient and family on patient admission to hospital. Strauss (1975:120) claims that, ". . . a hospital death means yielding to the staff virtually complete control over his (the patient's) care." Ex-patients have sometimes spoken of feeling almost like an imposition, depersonalized, like a number or a disease—'the terminal cancer in room 2047.'

According to Simpson (1979:103), "[In hospital] other people's expectations may weigh heavily. Staff and family may expect that the patient must remain calm, composed, and cheerful, and face death with his dignity (and theirs!) intact."

Kübler-Ross (1975:7) explains the situation further:

> In our modern technological society, dying is something you do in a hospital. But hospitals are efficient, impersonalized institutions where it is very difficult to live with dignity, where there is no time and place in the routine to deal with the human needs of sick human beings. Hospitals are institutions committed to the healing process, and dying patients are a threat to that defined role. The professionals in hospitals have specified expectations and routines to carry out; these simply don't work with dying patients. This is a threat to the professionals' roles and creates feelings of inadequacy which are inconsistent with their defined roles as people who can deal effectively with disease. There is no room in the prescribed roles of professionals for them to behave as human beings in response to their dying patients.

The predominant number of deaths occur in hospital and as Kübler-Ross suggests in the preceding description, the main thrust of the hospital in its current form is the treatment of disease. Health professionals' skills are used to investigate, diagnose, then cure the disease and they focus their energies on prolonging life. This is an appropriate focus for many patients, but for those who are terminally ill, a different plan of care with goals tailored to meet the foreshortened life perspective of the dying is needed. To strive for cure when cure is no longer possible contributes only frustration and alienation to both patients and care-givers and compounds existing problems.

The literature abounds with descriptions of the dying patient in hospital, being isolated, physically as well as emotionally. Greenley, in an unpublished paper sent to the author in 1980, reports on several instances of deficiencies in patient care:

> There is increasing evidence that patients who die in hospital and their families experience a wide variety of critical problems that often go unrecognized, the terminally ill patient frequently encounters isolation and depersonalization. The hospital staff also finds the situation difficult. Lasagna has suggested that the orientation of the medical team may foster a half-hearted approach in seeing to the welfare of the dying. Quint reported that nurses, in a study investigating how hospital nurses coped with death, did not welcome assignments to dying patients and were for the most part uncomfortable in conversing with them. Wegman reveals that encounters between nurses and terminal patients demonstrate more task oriented behaviors and more avoidance techniques than with other patients. As death approaches interaction between patients and staff becomes strained and patient care is affected. These deficiencies in the approach to the terminally ill were corroborated in a study of attitudes toward dying conducted at the Royal Victoria Hospital in Montreal.

Mauksch, in Kübler Ross (1975:7) comments further. The comments are summarized as follows:

1. The current culture of the hospital emphasizes the disease process and the diseased organ. If the patient is dying the diseased organ is not his primary concern; dying becomes a total experience, requiring total care. But the hospital is geared to rooting out the disease and it is very difficult to change the focus to comprehensive care that would allow a patient to die in an appropriate way.

2. The hospital is not designed to absorb and cope with the normal stages of anger, bargaining and grieving that the dying patient goes through. Patients feel dependent on professionals for information and for care.

3. There is also the phenomenon of "professional behavior" based on the myth that emotions are best controlled. There is a fear of showing compassion that blocks a display of the genuine concern that is present among many professionals who work in the hospital. The mask of cool detachment that health care professionals think that they must wear at all times causes them to feel frustration and guilt for acting in a manner that is incongruent with their true feelings. This dichotomy serves only to exacerbate the situation for both the terminally ill patient and the caregiver.

Simpson (1979:95) notes:

> One fear that both doctors and relatives have is that if they should begin to speak honestly about the patient's illness and fears, he "won't be able to take it" or "might break down" or "go crazy" or "commit suicide."

However, the evidence points to the fact that the fear of break-down is unfounded and that those patients who have been told their diagnosis have showed improved family relationships and less tension and upset in response to the progressive deterioration of their physical condition. Some patients, as previously described, even receive a new lease on life—as one patient said, "Suddenly life is far simpler. Now I'm free of all the rules" (Simpson, 1979:96,97).

As Huntington and Metcalf (1979:195) suggest, "The endless shying away from confrontation with mortality is undeniably a marked feature of [North] American culture."

Explanation of Present Status of Hospital Care

The literature on terminal care is critical of hospitals perhaps partly due to frustration on the part of caregivers and patients who feel caught in a system that is becoming increasingly complex. In fact, the most passionate comments appear to be made by the most idealistic of authors (Sarton, 1978; Cousins, 1983; Hatfield and Hatfield, 1985; Mount, 1986).

The author has been and is a part of the system that the literature so thoroughly criticizes and as recently as the summer of 1986 was again involved with a patient who died in hospital. In 1980 the following attempt was made by the author to understand the complexity of organizational care for the dying:

> Institutions have a tendency to take on a life of their own that may or may not be congruent with individual client needs. There are many possible explanations for this phenomenon. Clients or patients are seen as transients who come and go, whereas the institutions remains. A particularly strong leader may have influenced the direction of the organization by focusing on one aspect of the total mission and the focus remained intact, even though the situation may have changed. Cultural influences such as technological advancement may have been overwhelmingly intrusive, to the detriment of slow, orderly change and progress.
>
> There is another explanation that may be significant in health care organizations, particularly those in which patients may die, and that is the staff stress that comes from becoming personally involved with the patient. By focusing on curing the disease as

> an end in itself rather than on caring for the person in his totality, the staff builds in an element of detachment and thereby, we believe, self-preservation. (See Assumptions and Principles Underlying Standards for Terminal Care, Appendix 2.)

However, Cicely Saunders (1967) believes with Greenfield (1981) that organizations are people and as such can be changed by change of administrative and staff perspective and attitude. Saunders (1967:21) writes:

> The last stages of life should not be seen as defeat, but rather as life's fulfillment. It is not merely a time of negation but rather an opportunity for positive achievement. One of the ways we can help our patients most is to learn to believe and to expect this.

The detachment of staff from the experience of the dying person may in fact have more to do with discomfort that comes from lack of preparation and knowledge than with lack of will. According to Millett (1979:146),

> [Another] problem has been the need to re-educate health care professionals regarding the concept of hospice. Allowing a patient a natural death without the use of technology to prolong his or her life is a notion foreign to many.

Hospice as an alternative concept of institutional care was introduced in Chapter 1. Between 1974 and 1986 in Canada alone, over 200 hospice or palliative care programs have developed yet obviously there is more to be done. The current state of the art of care for the dying is described and explicated further in the Spring, 1986 Newsletter of the Alberta Heritage Foundation for Medical Research. A recent speech by Balfour Mount on the status of terminal care is summarized. Mount makes the following points:

1. Seventy percent of us die in institutions and we die badly.

2. Modern institutionalized medicine has superbly succeeded in postponing death but once the inevitable is imminent, too often health care professionals have not known how to use technology, psychology, or personal resources to care for the dying. Hospitalized patients die "badly" because they die in more pain, more loneliness, and more anxiety than is necessary.

3. Research has shown that palliative care benefits the patient physically, emotionally, and spiritually, and reduces subsequent illness in the bereaved.

4. People in palliative care have reason to be proud of their successes in the last 15 years, but for all its successes palliative care still has a long way to go.

The Hospice Perspective on Terminal Care

Before looking at where palliative care or hospice should be going, however, it is useful to make a succinct statement about how hospice differs from the hospital method of providing terminal care.

Although the author has been reading the literature on hospice for over seven years, the following way of differentiating the forces that drive the traditional hospital and hospice institutions to quite different models of care is the most succinct explication yet found. The synopsis is called Philosophical Differences Between Traditional Health Care and Hospice, the Delegates Manual, Association of Community Cancer Centers, November, 1978 and is included in its entirety. The a vs. b stance that writers of the synopsis take tends to polarize and generalize and is an obvious flaw. However, the issues orientation of the paper serves to demonstrate the way proponents of the hospice movement tend to view the hospital way of dealing with dying patients.

PHILOSOPHICAL DIFFERENCES BETWEEN TRADITIONAL HEALTH CARE AND HOSPICE

	TRADITIONAL	HOSPICE
(1)	Denial of Death.	Death in perspective as part of the life cycle.
(2)	Cure at all costs. Aggressive investigation, therapeutic intervention. Sustaining all systems and prolonging life.	"The capacity to act does not justify the action." Not shortening life but also not prolonging dying. Reality faced in consideration of appropriate therapy.
(3)	Emphasis on technology and new technological advances. Some radical procedures in terminal cases have been described as treating the doctor—not the patient.	People oriented and patient-centered. Emphasis on concepts and details of care. Skilled medical care in relief of symptoms, expert bedside nursing care and a multi-disciplinary team approach.
(4)	Emphasis on the disease process.	Emphasis on the patient as a person and a family member.

(5)	Emphasis on Quantity of life.	Emphasis on Quality of remaining life.
(6)	Emphasis on defeat. When decision is made that "nothing more can be done", case is considered a medical failure, and patient is filled with anxiety, depression and despair.	Emphasis on opportunity. There is always much that can and should be done to relieve pain, other symptoms, distress, fear and isolation. This can be a period of growth for the patient, family and staff.
(7)	"Terminal" patients are frequently isolated, away from patients expected to live and from their families, and deserted by their physicians. Nurses take longer to answer these patients' bells.	Communication and support emphasized. More than normal nursing hours per patient per day. Major contribution by volunteers. Families participate in the care. Visiting hours unlimited and children permitted. Family may stay overnight in crisis periods.
(8)	"Conspiracy of silence" practiced. Diagnosis, prognosis and discussion of these tend to be withheld.	Patients and families encouraged to come to terms with reality, to plan the death rituals and the family's future, to proceed with "unfinished business" and participate in anticipatory grief.
(9)	Physical systems maintained with intravenous fluids, forced feedings, nasogastric tubes, laboratory examinations and x-rays. Temperatures, pulse, respiration, blood pressure taken regularly. Regular eating and sleeping times maintained.	In most instances all these are discontinued as unnecessary and not contributing to the comfort of the patient. Primary concerns are comfort, mobility, participation (quality of life), eating what and when they wish. Laughter, parties, celebrations encouraged.
(10)	Therapies and life-support systems normally continued.	Symptomatic treatment only, such as radiation therapy for reduction in tumor size, or nerve blocks for relief of pain, or administration of oxygen to ease breathing but not prolong life.

(11)	Pain treated with limited amounts of medications on PRN basis. Fear by physicians of psychological dependence, addiction. Goal reduction not elimination of pain.	Major emphasis on pain control. Studies showed addiction not a factor in chronic pain unless medication withheld. Careful and continual titration of amount of narcotic to individual needs, prescribed for administration at regular intervals around the clock to eliminate pain and the fear of recurrence of pain, while maintaining normal affect. Ease of administration emphasized for patient mobility and independence. Emphasis on relief of side effects of narcotics, especially constipation and nausea.
(12)	Acute care wards, nursing homes, or unattended care at home the alternatives for terminal patients.	Emphasis on patient at home and dying at home if patient wishes and if possible. Maintenance at home supported by home care multidisciplinary team and 24 hour 7 day a week staff availability.
(13)	Fragmentation of care. Little communication between various staff caring for patients at various hospitalizations. Different nursing staff caring for same patient each day. Staff shifted from ward to ward.	Continuity of care. Patient not abandoned whether in home or in hospital. Staff consistent, continuing care of same patient. Staff not shifted to other departments. Complicated medical and family problems sorted out by multi-disciplinary team with patient and family participating.
(14)	Little attention directed to treatment of patient's diminishing resources, self image and self confidence as disease and disfigurement progress.	Greatest possible feeling of well being and self-worth encouraged. Physical, occupational, speech, music, drama and recreational therapies employed.

(15)	Depersonalization. Patients expected to fit into the system and follow regulations.	Patients encouraged to express individuality, wear own clothes, maintain own idiosyncrasies. Allowed to die as they lived, not according to a predetermined mold.
(16)	Terminal emotional support relegated to clergy and chaplains, not always skilled in this work.	Consideration of spiritual matters encouraged but not forced. Openness, and acceptance of the patients "where they are" rather than "where they should be". All staff participates not clergy alone (all are team members).
(17)	Staff seldom supported or educated in terminal care. Isolated.	Team meetings, staff support systems, and continuing inservice education an important emphasis.
(18)	Care is one way—for the patient. Patient's opinion not invited.	Participation of patient is encouraged. Patient contributes to knowledge and understanding of family, and of staff.
(19)	At the death, all contact with the family ends.	Frequent staff attendance at funeral. Continued support of family through Bereavement Follow-up Program, to facilitate grief work and to identify serious problems.
(20)	Structured educational programs in professional technical expertise. Continuing technological research.	Widespread multidisciplinary educational program for professional staff, students and the public in the philosophy and practice of hospice. Initial and continuing research and evaluation in patient needs, all aspects of care: medical, social, psychological, spiritual, financial, and also analysis of alternative structures and financial coverage.

Problems with Planning Responsive Institutional Care

Hospice has become increasingly supported by oncologists and others working in treatment facilities (McDonald, 1984). Yet, there is a lag in implementation of hospice programs. Hinton (1979) suggests a reason for the apathy and resistance facing planners of terminal care. Hinton (1979:32) reports in The Lancet on the results of a major survey on terminal care: "No policy could be final: listening to people during this study confirmed that human reactions to dying are often ambiguous and inconsistent."

The hospice philosophy of care includes inhouse and home care as possible sites for providing care. Patients and families and health care professionals tend to view the terminal state quite differently and therefore institutions that would be responsive to needs expressed by these stakeholders may be difficult to design. For example, Wilkes (1984:900) found in his research that "Health professionals and relatives differed considerably in their assessment of the same case. The difficulties of relatives were more often the cause for hospital admission than those of the patients."

Hines (1979:175) reports that, "While people say they would like to die at home, there is widespread uncertainty on the part of dying people and their families that this is consistent with the best care." Hinton (1979:32) states that:

> Patients gave most praise to the outpatient system of care [home care] despite experiencing a little anxiety or irritability at home. In contrast, relatives' comments on the usually welcome tranquility of those dying as inpatients [in hospital] sometimes had a slightly disconcerting obituary glaze which obscured personal foibles and even the texture of human character.

There appears to be a difference of opinion between patient and family about the best place to be during the last difficult period of care.

As Wilkes (1984:952) notes:

> The differing perceptions of problems by different individuals caring for the same patient reinforce the need for more integrated care and a knowledge of, and respect for, the views of those involved, including patients and relations.

Current Perspective on Research into the Dying Experience

Patricia Parks (1980:102), Division of Medical Services, American Hospital Association, issues the following challenge:

> Hospice care must learn to separate facts from assumptions. Hospice care assumes that most patients wish to die at home, that these patients do not wish any heroic treatment when "cure" seems unlikely, and that family members and friends are capable and willing to care for their dying loved one. Some proponents will add that hospice care must remain outside hospitals in order to retain the integrity of the concept. How valid are these assumptions? How practical and realistic are they?
>
> The possibilities for research in hospice care are many, such as the practical areas of patient-staff ratios, the number of beds that are needed per program, and the efficiency of pain-controlling drugs. Like all disciplines, however, hospice

> care must answer some basic questions before it proceeds into any other type of research.

As noted in Chapter 1, this inquiry focuses on one element of hospice, the family experience of terminal care. The study centres on the family perspective on dying at home.

Rainey et al. (1984:201) concurs with the belief in the importance of the family perspective on terminal care:

> Health care planners concerned with hospice concepts and services must be responsive to economic forces, government policies, demands of sponsoring institutions, and the proclivities of the professionals and volunteers who staff the program. Within this matrix of forces, however, one cannot afford to ignore "consumer opinion."
>
> Further research on options in terminal care is needed, including assessment of attitudes held by family members of the terminally ill.

The Family as Informant

A thorough search of the literature to help the author map the domain of inquiry shows that several studies in the general area of the family experience have in fact been completed. Studies have been done on family members of the patient dying in hospital (Hampe, 1975; Friehofer and Felton, 1976; Dracup and Breu, 1978; Putnam, 1980). These studies used questionnaires, Q-sorts, and structured interviews to elicit data. The experience of the family member caring for the dying patient at home, however, is likely to be quite a different experience.

Research on the home experience of family caregiving has for the most part consisted of needs assessments based on anecdotal evidence gathered incidental to the caregiver's work or professional experience (Malkin, 1976; Matthews, 1980; Dobihal, 1980; Martin, 1981). Experience is a valuable asset to the research but the results of these studies may lack the benefits gained from the relative objectivity of the researcher who has a research plan and purpose.

Rose (1976) did a thorough study of 26 spouses using a questionnaire/structured interview approach but her study was retrospective and there is some concern about the accuracy of retrospection of a process of the magnitude of death of a spouse. Retrospection is useful as a therapeutic exercise for the family members which in some measure offsets the intrusiveness of this difficult topic of research. However, experience in working with the bereaved leads the author to question the accuracy of information elicited particularly by questionnaire after the death, when it concerns the actual experience of caring for the dying as it was in process. Retrospection is useful for purposes of comparison and questionnaires may be of some benefit if used as an adjunct to personal contact, however being with the family during the process must be considered a more reliable source of data.

Martinson et al. (1976) and Edwardson (1983) have done thorough research on a pilot project undertaken to assist families care for a dying child at home but the experience of caring for a child dying at home with the support that was possible due to the funding received for the pilot project would, it is suspected, be not necessarily an easier experience but a different study from the research undertaken in the present inquiry.

A major part of the preliminary review of the literature was developed from The International Bibliography on Palliative Care (1983). Additional Med-Line and Psychological Information computer searches were made of the literature (1980-1984) on the family perspective on caring for the dying patient at home. Although thirty-five different studies were on file, these searches verified the author's previous findings guided by The International Bibliography on Palliative Care (1983).

One report, The Experience of Giving Care to a Parent Dying of Cancer: Meanings Identified through the Process of Shared Reflections (Gray-Snelgrove, 1982), an unpublished dissertation from the University of Toronto, was a valuable source of information in that it was written with sensitivity and the authenticity gained from personal experience. However, this study too was retrospective.

It was apparent from the titles and descriptors of the other thirty four studies that two studies were in a foreign language, seven studies were from the professional caregiver's point of view, three studies focused on children or the geriatric patient, ten studies dealt with the effects of hospice programs on the family, two studies focused on the patient and eight studies looked at only one aspect of the family member's experience such as bereavement. (One study was cited twice.)

Although Vachon (1980) has thoroughly researched and documented the experiences of the professional caregiver working in palliative care, it appears that with the exception of writers such as Mount (1983), who writes movingly of his own experience of watching his mother die at home, there is a dearth of information about the experiences and the meaning of those experiences to the family member who is responsible for the care of a dying relative at home.

Current Research in Related Fields

Archbold (1982) has done exploratory work on caring for an aging parent at home. Archbold studied the impact of "parent caring" on thirty women. The results of the study, although problem oriented, are instructive, particularly in the later stages of the current study for the purpose of comparisons to related theory.

The Domain of the Inquiry

After a thorough search was made of the current literature in the field of home care for the dying, it is concluded that there is an apparent lack of inquiry into the experience of living with and caring for the dying person at home as seen from the family member's perspective, during the time that care is being given. The question guiding the research therefore became: What are the experiences of the family member who is primarily responsible for the care of the person dying at home?

The researcher inquired not only into the experience but also into the meaning of the experience to the family member who was providing care and support of the dying patient. Contextual and nonverbal indicators related to the experience were also of interest to the researcher and were observed during the on-site visits and recorded immediately after the visit.

The findings from the inquiry led to the development of an evaluation model that is consistent with the philosophy of the inquiry and is responsive to the experience of the family. Confidence in the timeliness and the relevance of this study is enhanced by the remarks made in February 1986 by Balfour Mount, an acknowledged leader in the hospice movement. The interview with Mount is reported in The Alberta Heritage

Foundation for Medical Research Newsletter (Spring, 1986: 14). The interview is included in its entirety. Underlining is done by the author to highlight the concerns that coincide with the focus of this present study.

> Research Important
>
> With palliative care established in 200 centres across Canada, what are the most critical needs? Mount would say: research, trained personnel, and adequate evaluation of programs. We need more research on the sources and methods of controlling pain, more studies of the effectiveness of bereavement counselling to reduce the illness and family breakdown that is associated with death in the family, and more research focusing on all the aspects of whole person care.
>
> Canada has many centres, but not enough trained personnel to staff them. "Can you tell me one other area in medical practise where the physician is expected to travel by the seat of his pants?" asks Mount. "These are our sickest patients with complex needs that require competent, skilled medical care. We are not just talking about sentimentality and hand-holding, but complete medical care, adding to that the psycho-social and spiritual issues."
>
> One of the goals of the forthcoming Canadian Institute of Palliative Care is to urge medical schools to adequately incorporate PC training in their curricula.
>
> Evaluation of medical care is a critical factor. Mount stresses that the highest clinical competence is required if abuses in PC are to be avoided. Just to have a PC program is not enough. Mount summaries a key point, "Palliative care services can never be an excuse for medical mediocrity."

Chapter 3 presents further information on the research design and methods used to elicit and interpret data in the current study of the family's perspective on dying at home. It is the author's contention that the research design and method as well as the study's focus meet with the criteria expounded previously by Mount and Scott (1983) and by Mount (1986).

Chapter 3

RESEARCH METHODOLOGY AND PROCESS

Introduction

A review of the literature on research methodology that probed the fields of education, nursing, psychology and anthropology was explicated in Chapter 2. It was determined that a qualitative method of research was the appropriate manner of inquiry. Qualitative research according to Bogdan and Biklen (1982:2) is:

> . . . an umbrella term to refer to several research strategies that share certain characteristics. The data collected has been termed soft, that is, rich in description of people, places and conversations, and not easily handled by statistical procedures [researcher as the instrument for data collection]. Research questions are not framed by operationalizing variables; rather they are formulated to investigate in all their complexity, in context [inductive]. While people conducting qualitative research may develop a focus as they collect data, they do not approach the research with specific questions to answer or hypotheses to test [hypothesis generating]. They are concerned as well with understanding behavior from the subjects' own frame of reference [the emic perspective] . . . They tend to collect their data through sustained contact with people in settings where subjects normally spend their time [naturalistic].

The work of Bogdan and Biklen (1982) is used as a framework for this chapter on Research Methodology and Process. Excerpts from other works from the disciplines of education, nursing, psychology and anthropology are used to supplement the description of research, methods and procedures used in the study.

Plan of the Chapter

The chapter begins with definitions of terms as they are used in the chapter, an overview of the research process and the rationale for choosing a qualitative approach to the inquiry. The research process is then described, from the selection of an 'umbrella' agency through data collection and data analysis. Developments such as the issue of confidentiality, changing roles of the researcher, triangulation of data sources, issues of objectivity, validity, reliability and ethical concerns are addressed.

Definition of Terms

Primary family caregiver is the family member or 'significant other' who is designated by the health care system as the key person responsible for the patient's care while the patient is cared for at home.

Key and ancillary informants. The definition as cited in Field and Morse (1985:138) is used in this study.

> Members of the social or cultural group in the research context who provide information and assistance with the interpretation of the setting. A key informant is the informant from whom the majority of the information is obtained. Secondary

> [ancillary] informants are [interviewed] by the researcher . . . [in order] to widen the data base.

Coding. The definition as cited by Field and Morse (1985:137) is used in this study. "The process of identifying persistent words, phrases, themes or concepts within the data so that underlying patterns can be identified and analyzed."

Overview of the Study

The purpose of this study was to focus on one dimension of hospice care; the experiences of the family member who was primarily responsible for the care of the person dying at home. The researcher inquired not only into the experiences of the caregiving but also into the meaning of the experiences to the family member. The goal of the research was to incorporate the findings as baseline data to enhance the work being done at present in evaluation of hospice programs.

Phase One of the Research Process

The setting of the first phase of the study was a suburban health unit. The unit provides palliative home care to both urban and rural clients. The initial key informants, three primary family caregivers, were between forty and fifty years of age, each caring for an adult relative dying at home.

Willingness to participate based on information about the purpose of the study, an explanation of the possible risks and benefits, and permission to withdraw without in any way jeopardizing the professional care being provided was assured. All key informants for the study agreed to and signed consent forms that assured them of this protection.

Following the guidance of Bogdan and Biklen (1982: 67), five other key informants were chosen from another setting because they were believed to "facilitate the expansion of the developing theory." These informants ranged in age from forty to sixty-five years of age and provided caregiving to adult patients.

The study is inductive and descriptive and used qualitative methods of gathering and analyzing data. Data were collected from the first three informants in unstructured, taped interviews with the informants primarily in their homes, from observations of contextual and non-verbal indicators related to the experience and from documents such as diaries and charts made available to the researcher (Bodisch and Lynch, 1983). The tapes were transcribed and analyzed using a line-by-line method which will be described at a later point in this chapter.

The data gathered at each visit were analyzed close to the time of the visit. Categories and themes were identified by the researcher. Subsequent visits were used to ask the subject if the identified themes reflected the experience in order to increase the reliability of the analysis, as well as to gain additional understanding of the caregiver's experience.

Phase Two of the Research Process

As mentioned previously, it became apparent that the inquiry demanded further and different kinds of involvement on the part of the researcher. The role of interviewer and observer in Phase One developed into that of interviewer and participant observer. Taping and transcribing data that provided the major means of collection in Phase One became an unwieldy device for data collection in Phase Two. The researcher became a "short note researcher" as field notes and memoes became the more appropriate method of retrieving impressions and insights that resulted from a multitude of events and research opportunities (Stern, 1985:154).

The circle of data gathering widened to include ancillary informants. The researcher was invited to participate in family gatherings on several occasions and these events became rich sources of understanding of another side of the caregiving experience.

The perspectives of patients, other family members, professional homemakers and primary professional nurses were also proving to be useful as their experience provided social context to the primary family caregiver's perspective which was still the researcher's major concern (Mishler, 1979; Field and Morse, 1985).

Time was spent interviewing and participating in spontaneous and organized functions that ranged from an unforgettable afternoon session with a dying patient ("Do you want to know what it's like to die? I'll tell you what it's like."), to helping a homemaker fold socks while hearing about her fears and responsibilities. Toward the end of Phase Two, four full-day workshops for professional caregivers provided further opportunity for an exchange of information as home care nurses and other professionals discussed dying patients' and family concerns.

The time was well spent with these ancillary informants. Although these informants are not designated as key informants, their appreciation of the primary family caregiver's experience added to their own experiences, enriched the findings. Jick (1979:602,603) recommends this ". . . use of multiple methods to examine the same dimension of a research problem." Jick claims that in this way "elements of the context are illuminated." Jick (1979:609) suggests that "Different viewpoints are likely to produce some elements which do not fit a theory or model. Thus, old theories are refashioned or new theories developed." Patients, homemakers, and professional caregivers, in speaking of their own experiences, shed light on the experiences of the family caregiver.

The key informants increased in numbers to eight in total and were chosen in a purposeful way (Bogdan and Biklen, 1982). Field and Morse (1985:95) define purposeful or theoretical sampling as follows: "Such informants have specific characteristics or knowledge which will add to, support or refute (i.e., negative cases) the theory, thus enhancing the researcher's understanding."

Glaser and Strauus (1967) open the way to further investigation. Glaser and Strauss (1967:65) write:

> . . . theoretical sampling for saturation of a category allows a multi-faceted investigation, in which there are no limits to the techniques of data collection, the way they are used, or the types of data required.

Glaser and Strauss (1967:69) continue:

> Theoretical sampling, though, does not require the fullest possible coverage on the whole group except at the very beginning of research, when the main categories are emerging—and these tend to emerge very fast. Theoretical sampling requires only collecting data on categories for the generation of properties and hypotheses.

Glaser and Strauss' (1967) statements support the way this current study developed. The pace in Phase Two quickened as many people in different positions in different groups were questioned about the same topic. Observations, interviews, documents, articles and books because sources of data and understanding.

As previously mentioned, near the end of Phase Two, the researcher was invited to give workshops on the research findings to four different palliative home care units.

The four units provided home care service to north-central, western, eastern and south-central Alberta. These invitations and positive evaluations are taken as further evidence not only of the interest in the topic under investigation but also that the findings, the family caregivers' experiences, were perceived as truthful and relevant to professional care providers in the relatively new Palliative Care Programs throughout the province.

Phase One and Phase Two lasted for a relatively hectic one and one-half years. The researcher, perhaps prematurely, presented papers to local and international nursing practitioners and educators. Critiques included warm agreement and cool criticism, both of which assisted the researcher in refining the final document. Apathy, at least, was not evident. As Bogdan and Biklen (1982: 57) suggest, "Self-discipline can only take you so far in research. Without a touch of passion you may not have enough to sustain the effort to follow the work to the end." However, Bogdan and Biklen (1982:57) also warn the 'passionate' researcher that, "while the choices are endless, some advice is in order. The first is, be practical. . . . Try to limit the number of hours you clock in and the number of pages of data you review." Balance and time for reflection are necessary components of the research process.

Phase Three of the Research Process

The researcher by September 1985 felt 'super-saturated' by data and experience and withdrew from the field for a time. A trip to an Israeli hospice where they had no resources except a quonset hut and good staff and several months of home caregiving twenty-four hours a day, seven days a week to the researcher's own ailing mother, were high and low points of 1984-1985. The experience had become too "thick" and personal. Some distance was necessary. Therefore a hiatus as education consultant at Alberta Hospital Association allowed time to 're-group,' read and visit the one remaining family in which the patient survives beyond the time expected by caregivers and patient alike. Margaret Mead (1976) endorses the necessity of self-awareness and reflection. Mead (1976:905) writes: "human beings . . . have the capacity to understand their fellows because they are sufficiently like themselves so that attention to their own internal states provides information about the internal state of others."

Glaser and Strauss (1964:65) sum up the researcher's experience: "He has not only been sufficiently immersed in the world to know it, but has retained enough detachment to think theoretically about what he has seen and lived through."

Phase Four of the Research Process

The writing of the document becomes possible. Anger at Death for causing dying and at the System for how dying sometimes happens has partially dissipated. Or perhaps as Bogdan and Biklen (1982:172) suggest, "Novice writers are big procrastinators. They find countless reasons not to get started." For whatever reason, the writing starts and follows the guidance of Glaser and Strauss (1967). Glaser and Strauss (1967) suggest that in the writing, one uses direct quotes and telling phrases from interviews and field notes. Events and acts are described with background word pictures of place and space, sights and sounds included, in order to convey the meaning and context of the experience. Bogdan and Biklen (1982) suggest the inclusion of vignettes that demonstrate the themes.

The findings are reported in a manner consistent with the nature and the purpose of the study. The language used is as simple or as complex as the datum itself so that the study cuts across professional boundaries and is available to the 'consumer' of health care and the administrator alike. Jaspers (1963) and Stake (1978) vouch for an informal style of writing that invites the reader to become a friendly participant; one who will try to feel and become engaged with the unfolding narrative.

To offset the propensity of the researcher/author to become overly involved and to "go native" (Field and Morse, 1985:93), five readers were enlisted to critique specific parts of the document. Two readers are nurses (content experts) who are involved in community health and home care, one reader is an expert in qualitative research methods and two readers are lay persons who have frequently served as correctives to the author's tendency toward an excessive flamboyance in style.

Bogdan and Biklen (1982:55) summarize the overview of the research process for the author:

> A strategy qualitative researchers employ in a study is to proceed as if they knew very little about the people and places they will visit. They attempt to mentally cleanse their preconceptions. . . . Plans evolve as they learn about the setting, subjects and other sources of data through direct examination. A full account of procedures is best described in retrospect, a narrative of what actually happened, written after the study is completed.

Entry to the Research Site: The Process Described

Selection of an 'Umbrella' Agency

The process of gaining entry to an appropriate health care agency was initiated in late spring 1984. A preliminary meeting was held at a major health care facility that serves a large population of critically ill and terminally ill patients. The initial meeting ended favourably but a follow-up phone call to the head nurse (HN) of the community wing of the program made the researcher realize that the collaboration would be difficult.

The researcher explained the proposed study to HN. The response was friendly but critical of the process. HN thought that anything other than a retrospective study would be "unethical." She thought that "home deaths are too difficult." "Families do not receive support." "Friends drop off because they are appalled at the idea of death at home." HN had approximately thirty "very ill" home care patients on her case load but "I'm not willing to call them dying." She suggested that I do a study on quality of life for families living with advanced disease.

My field notes on that occasion read: "I am beginning to see why I can't find any studies done in this area. Too difficult to get through the system." "Dis . . couraged."

During the same period the researcher and the Director of Home Care at the Suburban Health Unit (SHU, which is a pseudonym) were on a panel together discussing Hospice for a community group. The Director asked what the researcher was doing at the present time. On hearing of the need for an umbrella agency for the research, the

Director suggested that a proposal be sent to her. The SHU had a new palliative care program and she would be happy to take the proposal to the Medical Officer of Health and the Board on the researcher's behalf. Within two weeks a letter arrived saying that the research had been approved by the staff and the Medical Officer of Health (MOH) (Appendix 3). A meeting was arranged with the staff and the MOH and a warm welcome was extended to the researcher.

Selection of Primary Family Caregivers: Phase One

The researcher consulted with the Director of Home Care at the SHU about the selection of potential families for the researcher to visit. Criteria for selection were developed.

1. It was necessary for the family and the patient to have acknowledged the fact that the patient's life span was limited to a few months. The ethics of this statement are dealt with under the heading Ethical Issues. The practical aspects of the statement have been dealt with by Amado, Cronk and Miles (1979) and by Gotay (1983).

In the Amado et al. (1979:523) study on cost effectiveness of hospice vs. hospital care, the population selected were

> Persons . . . diagnosed by their physicians as terminal, with a life expectancy of roughly two months. The patient may have completed a program of medical, curative treatment that has not resulted

> in cure, and the focus of care has shifted to comfort.

Amadeo et al. categorized their large sample into Stage One 'Terminal—but family can largely manage' and Stage Two 'Imminently Terminal—family cannot manage even routine care.' Ninety percent of the sample were cancer patients. Gotay (1983), in her study on "Home care for the dying: Homemakers' perspective," found that the average length of home care for the dying was nine weeks.

2. The selected family members, primary family caregiver and patient had to be fully informed about the research purpose and process and be given the opportunity to agree to participate or to decline to assist in the research project with no fear of penalty. All key informants in fact as the study progressed were fully informed about the project and agreed to sign the consent form (Appendix 4).

The researcher was assigned to a home care nurse from the Unit. Over the summer, selection of informants and protocols were discussed. The researcher was invited to come to the Unit August 31, 1984, meet and have lunch with all home care staff and start that afternoon to visit potential informant families.

Entry to the Homes of Primary Caregivers: Phase One

The protocol that had been developed over the summer worked well. The home care nurse, starting with three families who met the research criteria, had talked to the family members (including the patients) about the research. She had asked permission to have the researcher visit to explain the project further. On August 31, the researcher visited two of the families with the home care nurse. By September 14, the first three families were selected. All families who were asked agreed to participate. The 'family-focused' part of the data collection began.

The population was selected for this study using the Amado et al. and Gotay studies as guides in subject selection. The families selected were on the Suburban Health Unit's new Palliative Home Care Program (Terminal, Stage One), the patients were dying of cancer and were considered to have a very short life-span (perhaps two months). An interesting dimension that adds realism to the data is that the three family informants were the first three families the home care nurse received as 'cases' in the new Palliative Home Care Program at the unit. The participating informants are introduced in more detail in Chapter 4 of the document.

Permission to Return: The Consent Form

After the initial visit, the researcher made an appointment to visit on her own at a time convenient to the family. Most visits from there on included a 'first stop' with the patient. The time spent with the patient seemed a natural and courteous part of the visit. The researcher then typically went to the kitchen or dining room table where the family caregiver would invite the researcher to have tea or coffee before beginning the "session." In fact, these two steps became something of a comfortable ritual for both researcher and informant.

On the second visit to each family, the consent form was explained and signed. The researcher asked permission to set up the tape recorder (the use of taping as a means of data collection had been discussed in the initial visit), and the 'formal' session began. The family caregiver was invited to "tell me about your experience of looking after ________."

There was no problem encouraging participants to talk about the caregiving experience. Interviews frequently lasted two and one-half to three hours or longer. Field notes and memos captured some data that were lost as tapes occasionally ran out at inappropriate times and there was delay in changing tapes and restarting the recording.

Field notes were also made on contextual and non-verbal information. At times the field notes became interesting and telling evidence of the larger truth behind "brave" words. For example, busy activity at a crucial moment in the interview such as wiping down an already immaculate microwave oven was an interesting event. The activity when placed in juxtaposition with a family caregiver's expression of wanting to be with the patient during hospital treatments became instructive. It later came out that being with the patient during treatment was exceedingly painful to the family caregiver. The patient sensed this discomfort in the caregiver and this perceived lack of support had repercussions during the later stages of home care.

Informants were asked to "jot down thoughts" and reflections between visits so that 'afterthoughts' would not be lost. The request resulted in a collection of notes that included poetry and "useful thoughts." The occasional ~~phone call provid~~ed the researcher with further data. There was a prevailing sense that the primary family caregiver had a need to talk with someone outside the family.

The Following Visits: Phase One

The visits continued with the first two families until after the death of the patients (three visits and two bereavement visits each after the death of the patients). The third patient is living at the time of writing (August 1986) and the researcher continues in relationship with the family. The researcher had been invited to meet with other members of the family of all three Phase One families during the data gathering process.

All visits except two were at the family caregiver's home. The expected problem with lack of privacy did not become a problem as patients were out of earshot (upstairs or down the hall). On at least three pre-bereavement visits the patients were temporarily in hospital for pain or symptom control. On one of these occasions, the interview was held at the acute care treatment setting which proved very useful as a source of comparative data. The other occasion was a lengthy interview held at the SHU so that the family caregiver could "just get away for a while."

Data Analysis: Phase One

Because the family caregivers lived some distance from the researcher's home, the driving time was used to listen to the tapes and to re-live the visit. Upon arrival home, the researcher listened to the rest of the tape, made notes, and shortly thereafter delivered the tapes to an experienced typist to transcribe. The transcripts were typed according to the format recommended by Field and Morse (1985), i.e., a one inch margin on the left of the page, a one and one-half inch margin on the right side of the page. The informant's and the researcher's words were single spaced with a double space left between interchanges for ease of coding. Pauses, laughter and other audible non-verbal content were included in the transcript for accuracy of coding.

Five copies of the transcripts were made. Copy one remained intact and was stored with the tape in a locked cupboard away from the researcher's home. Copy two went to the auditor for independent coding. Copy three was used by the researcher to code during the initial independent coding stage in conjunction with the auditor. Subsequent coding that required further cutting and pasting as themes developed was done by using the extra copies of the transcripts.

The transcriptions were colour coded by informant and by interview number in sequence. Bands of colour were put down the left margin of the transcripts so that cut portions were readily identifiable. For example, informant number one was coded purple, and the first interview was coded blue; the second interview was coded green. Therefore the first interview with informant number one had one band of purple and one band of blue down the left side of the pages of the transcript. The second interview with informant number one had a band of purple and a band of green. Field and Morse (1985:102) elaborate on the colour coding method of data analysis:

> When analyzing the data, cut the significant passages from the interview, tape each piece onto a full size sheet of paper and file it in the appropriate folder for that category. The colour coding is a fast method of identifying all data, allowing pieces coded for analysis to be traced to the original source. Cutting the transcript enables the data to be quickly sorted without the necessity of rewriting the appropriate passage onto another card. However, as one segment may fit into two or more categories, the need for several copies of data is obvious. As the file folders fill, the contents are again sorted into smaller categories.

The auditor and the researcher independently scrutinized the transcripts line by line, and developed categories for the data. At the meetings that followed, categories were discussed and it was found that there was close agreement. In any instance where there was disagreement, the researcher took the question back to the informant for the deciding judgement. One finding at this point was the value of field notes on non-verbal and contextual data. Non-verbal indicators and the transcribed pauses and signs of emotion such as uneasy laughter at times gave a more accurate recollection of the caregiver's response and true feelings about his or her experiences than did the actual words used.

Probe questions were developed in consultation with the auditor. The probes were used to elicit information from the family caregiver. In keeping with the sensitive nature of the inquiry the 'probes' were used in the context of the visit when further questioning 'felt' appropriate. (See Appendix 5 for samples of probe questions.)

Transcriptions and line-by-line analysis were used only during Phase One of the data collection process (nine interviews).

Phase Two of the data collection and analysis followed quite naturally from the need to branch out, to discover more about the processes that were becoming evident from the data analysis in Phase One. The branching process is described as it occurred.

Phase Two: Saturating the Data Base

Key Informants

Three other primary family caregivers, key informants four, five and six, were added during this time. These family caregivers were chosen because they were "believed to facilitate the expansion of the developing theory" (Bogdan and Biklen, 1982:67). There was no difficulty in finding informants. The Director of Home Care in an urban setting offered assistance. However, three appropriate and willing informants came to the researcher's attention by way of contacts previously made through work done in palliative care in the community.

The contact made with family caregivers four, five and six was less intensive and included three visits with caregiver number four, one visit with caregiver number five and three visits with caregiver number six. Consent forms were obtained from informants and data collected for the most part by field notes rather than by taping. Two hours additional taping was done with informants five and six. Phase Two informants were added because the relationship to the patient was different from that of informants in Phase One. Two of the informants provided retrospective data. Although there was no attempt to obtain a representative sample, the opportunity presented itself to balance the male/female representation and to find extreme situations that would be helpful for purposes of comparison.

It is by now common knowledge that the extended family living within helping distance is an increasing rarity. Therefore, the opportunity to interview a single man who became primary family caregiver to his American father gave the researcher needed information about extreme cases. The informant's family lived in Boston, the Alberta health care system did not cover home help for his father and some networking of the Hospice system became necessary. This seventh key informer provided information about the "cracks" in the system and how the family member feels and works his way through the system.

Supplementary Documentation

Bogdan and Biklen (1982:98) suggest that "The spontaneous, intimate diary is the personal document, par excellence (Allport, 1942:95)." "Because a diary is usually written under the immediate influence of an experience, it can be particularly effective in capturing people's moods and most intimate thoughts." The researcher was loaned a diary kept by a daughter whose father was dying at home and refused treatment and professional care of any kind until near death. Because the diary materials were written as the situation developed, this document is an unusually deep and insightful description of a kind not usually available to a researcher. For this reason the keeper of the diary is considered to be key informant number eight.

Bogdan and Biklen (1982:53) recommend the use of other documents to enhance the understanding of the experience under study. They write: "an important dimension of documents, particularly human documents is their ability to call forth not only an intellectual response, but also an emotional reaction. Documents . . . offer a glimpse of an inner existence, a private self." The researcher received several letters, notes, pieces of poetry, important sayings that are used when appropriate to enrich the description of the experience.

As previously cited, two homemakers who were care providers for two of the families were also interviewed to enrich the data base and to broaden understanding of the experience under study. The researcher was also in weekly contact with the primary home care nurse at the Suburban Health Unit and has kept in frequent contact with her over the past two years. The administrator of the unit and the nursing supervisor have both been available to discuss the changes in their roles as a result of the new interest in palliative care. These ancillary informants along with information gathered from the four workshops described in the earlier portion of the chapter assisted the researcher in the administrative aspect of the developing evaluation model that is an important part of the study.

In order to protect the identity of all informants, transcripts were coded by number and pseudonym which are recorded in Table 1. Relationship to the patient, total hours interviewed as well as sources of data beyond the interview are included.

Ethical Issues

The Concern

The ethics of this research is, in the most basic sense, the most important element of the study. The author has read extensively on the topic and has reflected on the risks and benefits to the subjects.

Agich (1978), although acknowledging the need for more than purely anecdotal research on the needs of the dying and challenging the researcher to go from style to substance and from rhetoric to action, at the same time makes a strong point in favour of respecting the privacy

Table 1

Summary Description of Informants

Subject Number	Pseudonym	Relationship to Patient	Key/Ancillary Informant	Total Hours Interviewed	Sources of Data Beyond Interviews
1	Joe	Husband	Key	31 +	Participant observation
2	Jennie	Daughter-in-law	Key	14 +	Participant observation
3	Salim	Husband	Key	9.5 +	Participant observation
4	Nicole	Daughter	Key	4	None
5	Charles*	Husband	Key	1	None
6	Ruth*	Friend-primary caregiver	Key	7	None
7	Bert	Son	Key	4	None
8	Alice	Daughter	Key	3 +	Diary
A	Colleen	Homemaker	Ancillary	3 +	Participant observation
B	Theresa	Homemaker	Ancillary	1	None
C	Laurie	Nurse	Ancillary	2 +	Averaged weekly contact during Phase One-Phase Two
D	Joan	Administrator	Ancillary	0 +	Continuing professional contact
E	Margaret	Daughter	Ancillary	3	None
F	Joanne	Daughter	Ancillary	2 +	Participant observation and documentation
G	George	Son	Ancillary	3	None
H	Nan	Patient	Ancillary	3 +	Participant observation
I	Mrs. W.	Patient	Ancillary	2	

*Note: Charles and Ruth are the only informants whose data are exclusively retrospective. All other informants include data collected simultaneously to the experience of caregiving to the dying patient with the exception of bereavement visits after the death of the patient.

of the dying patient and family. It in fact did not seem fair to just go and get the information from the family member, then leave with what was required for the researcher's purpose.

To somewhat offset Agich's well-taken point and the author's concerns, other researchers and authors such as Mathis (1974), Saunders (1965, 1976), Parkes (1980), Grollman (1980) and Scott (1981) strongly support the value of speaking openly with dying patients and their families about death. The conspiracy of silence and denial of death is seen by many in the field as more destructive than the truth. The sensitive issue of truth in appropriate amounts was developed from the literature in another study by the researcher (McHutchion, 1980). Parkes (1980) suggests that intrusion is more often a problem in the mind of the professional than it is in the mind of the client. Hampe (1975), in fact, found that spouses of patients dying in hospital were extending the length of visit beyond the researcher's need.

The Family Response

Although family caregivers are busy and preoccupied with the demands of their situations, they apparently benefited by "telling the story." As Thorne (1980) notes, field work has a reciprocity and an interactive flow that offsets the trauma and risk to subjects.

Before entering the field, a commitment was made to health unit personnel that if, in fact, the experience proved to be disturbing to the family caregiver, the researcher would ask permission to inform the appropriate resource person who would then be able to intervene. The researcher also provided her phone number to the informant as an extra precaution. However, the dilemma proved to be to the contrary: the problem was closure. When to leave the family and how to leave appropriately were concerns that were partially met by the evolving role of the researcher and by weekly calls to the family's nurse for a neutral estimation of how the family was in fact 'doing.' The home phone number was used on occasion to invite the researcher to participate in, for example, a celebration or to meet visiting relatives. As one family member said, "I like to bend your ear." It appears that the research experience was a reciprocal process for informant and inquirer alike.

Credibility of the Research

The Issue of Validity and Reliability

According to Leininger (1985:69), "at present, students of research are taught to use quantitative validity and reliability for qualitative studies. As a result, confusion, conflict, and other problems are evident today." Field and Morse (1985:116) elaborate:

> In any research the ability of individual researchers to demonstrate credibility is critical to the value

> of the findings. In all research reliability and validity of findings are important. However, the way in which criteria are used for assessing the reliability and validity of a study will vary with the type of research. The question raised regarding the reliability and validity of a descriptive study may be different from those addressed in a quantitative study because . . . subject selection, data gathering and data analysis are conducted in different ways and for different purposes.

At the present time, validity and reliability are the terms of choice, or perhaps necessity, in addressing the issue of quantitative or qualitative research credibility and accuracy.

Validity of the Research

Validity in quantitative research refers to "the degree to which an instrument measures what it is supposed to be measuring . . . measurement is the focus" (Leininger, 1985:68). Leininger (1985:68) continues:

> In contrast, I contend that validity in qualitative research refers to gaining knowledge and understanding of the true nature, essence, meanings, attributes, and characteristics of a particular phenomenon under study. Measurement is not the goal; rather knowing and understanding the phenomenon is the goal.

Field and Morse (1985:116) further describe validity:

> Validity is the overall concept used to refer to how good an answer a study yields. That is, is the answer provided by the research sound, and does it represent reality.

Leininger (1985:69) sums up the answer to the question 'Does this study represent reality?':

> Qualitative validity should rest upon knowing and understanding the phenomena as fully as possible rather than on the adequacy of the instrument and measuring the results.

Reliability of the Research

Bogdan and Biklen (1982:44) agree that "in qualitative studies, researchers are concerned with the accuracy and comprehension of their data." Reliability is an issue for discussion. These authors (1982:44) continue:

> Qualitative researchers tend to view reliability as a fit between what they record as data and what actually occurs in the setting under study rather than the literal consistency across different observations . . . two researchers may come up with different data and produce different findings. Both studies can be reliable. One would only question the reliability of one or both studies if they yielded contradictory or incompatible results.

Leininger (1985:69) develops the term further:

> In qualitative research . . . reliability focuses on identifying and documenting recurrent, accurate, and consistent (homogeneous) or inconsistent (heterogeneous) features, as patterns, themes, values, world views, experiences, and other phenomena confirmed in similar or different contexts.

Field and Morse (1985) acknowledge their indebtedness to LeCompte and Goetz (1982) and use similar criteria to explain the hallmark of a reliable qualitative research study. These authors agree that sample selection, social context, observer/researcher variables and methods of data analysis are essential considerations in supporting a positive answer to the question of reliability. Each criterion is developed further in the format of The Challenge to the Researcher and the Researcher's Response.

Sample Selection

The Challenge

Field and Morse (1985:117) recommend that "In all studies it is useful to verify data with information from several sources" (i.e., triangulation). Other elements these authors include as essential to reliable research are: Time: sufficient; Place: close to the people; Social Circumstance: variety of locations in which behavior is observed; Speak the Language: jargon that reflects the population under study; Intimacy: the researcher is allowed inside the informant's life; Consensus: agreement across informants; History and Maturation of the Group: changes over time in the setting and changes in the individual informant over time.

The Response

Triangulation: In the current study ancillary informants and a diversity of documentation provided a variety of data.

Time: Data were collected over a one and one-half year period.

Place and Social Circumstance: Home visits and following the family caregiver through different phases and events within the caregiving context were part of the study.

Speaking the Language: The research is familiar with the language due to personal experience with two home deaths (father and step-father) as well as work experience (over 200 home visits to bereaved families for purposes of assessment and referral).

Intimacy: The informants allowed the researcher to be a participant observer and in fact invitations were forthcoming to attend family occasions. A reciprocal relationship developed in which the researcher at times intervened with the system on the informant's behalf. The method of interviewing used is described and endorsed by Bogdan and Biklen (1982:43):

> Since interviewers in this type of research are interested in how people think about their lives, their experiences, and particular situations, they model their interviews after a conversation between two trusting parties rather than on a formal question-and-answer session between a researcher and respondent.

Bogdan and Biklen (1982:50) go on to say, "Doing qualitative research with subjects is more like having a friendship than a contract." Close relationships did in fact develop.

Consensus, History and Maturation of Group. The elements of consensus, history and maturation are more related to process than to isolated events. As previously described, the 'honesty' of the response at times came from a developing trust between informant and researcher. So called right answers, i.e., "I ought to feel" became "But I actually feel" as feelings of resentment, anger, etc. eventually surfaced. Time became an important factor that is developed further as a theme in Chapter 4 of this study.

Observer/Researcher Variables

The Challenge

The status of the observer, observer biases and observer effects are factors that must be registered for the reader's consideration.

The Response

A resumé of the researcher's credentials is inserted as Appendix 6 in the document. The researcher is a registered nurse with five years' experience in the area of bereavement and is also a certified psychologist who is familiar with interviewing and counselling techniques. The researcher has also been somewhat of a political activist, co-founder of Hospice Care Edmonton Society which had a history of lobbying government and professional bodies in the area of palliative care. It could be argued that the researcher's past experience presents a potential bias. On the other hand, experience and credentials proved to be invaluable as the researcher was perceived by the informants to be an ally and advocate and as such was entrusted with information that may not otherwise have been offered. It became necessary at times not to report data judged to be too sensitive.

Methods of Data Analysis

The Challenge

Field and Morse (1985) encourage the researcher to use low inference descriptors, participant review of findings and peer examination.

The Response

Chapter 4 of this study is basic in its descriptions of the informants. Verbatim accounts are lifted from the transcripts and field notes to develop the themes and categories. Participants have been asked to review and advise the researcher concerning accuracy of the data analysis and peer examination has previously been described.

As Glaser and Strauss (1964) suggest, the reader/critic will base his decision concerning credibility on the range of events seen, whom the researcher interviewed, who talked to him, experiences in the field and how he might have appeared to informants.

Another issue which frequently surfaces as criticism of the qualitative research study is the need and the lack of generalizability of the findings of other populations.

Generalizability of the Study

The Challenge and the Response

As Field and Morse (1985:122) state: "generalizability is not the purpose of qualitative research but the purpose is rather to elicit meaning in a given situation and to develop reality-based theory." Bogdan and Biklen (1982:41) agreed that generalizability is not thought of in the conventional way:

> [Qualitative researchers] are more interested in deriving universal statements of general social processes rather than statements of commonality between similar settings . . . The assumption is that human behavior is not random or idiosyncratic. They therefore concern themselves not with the question of whether their findings are generalizable, but rather with the question of to which other settings and subjects they are generalizable.

Generalizability as defined by Bogdan and Biklen (1982) is addressed in Chapter 5 of the study.

Summary

The purpose of Chapter 3 was to elaborate upon the research methods used in the current study. Avorn (1984), an economist writing in the prestigious New England Journal of Medicine, makes the following points that sum up this researcher's philosophy about the methods chosen for this study on palliative care. Avorn (1984:1294-1295) writes:

> Considerable enthusiasm has developed in recent years about the use of quantitative methods to guide the allocation of health-care resources . . . the past two decades have [however] seen a waning of the professional sovereignty of physicians and policy makers alike. Any method that proposes to reduce decision making of both groups to a standardized set of equations and alogarithms fits in well with the increasing public mistrust of the professions. Such an appeal also meshes nicely with the "corporatization" of health care, as well as the movement in the social and managerial sciences to measure as many variables as possible in an earnest (but sometimes hopeless) attempt to imitate the work of natural sciences.

Avorn (1984) goes on to remind the reader that we are a society not an economy and draws a sharp conclusion to the popular metaphor of the life-boat that has relevance to this inquiry. Avorn (1984:1300) writes:

> The metaphor was popularized by authors who likened the plight of society facing tough decisions on resource allocation to that of passengers on an overcrowded and sinking life boat who must choose who should be thrown overboard in order for the rest to survive.

Avorn (1984:1300) suggests that:

> A wider view reveals that the lifeboats are encircled by a fleet of destroyers and cabin cruisers, their decks filled with experts offering suggestions and commentaries on how such life-and-death decisions should be made. Instead of focusing on the content of the recommendations, energy would be better spent on redeploying the fleet to rescue some of the victims.

The current inquiry in fact takes Avorn's suggestion to the extreme and suggests that the "victims" may or may not need or want rescuing. The first task is to discover who the passengers are, to get acquainted with them and describe their situations in an informal style of writing that invites the reader to become a friendly participant, one who will try to feel and become engaged with the unfolding narrative.

Chapter 4 is in substance an introduction to the key informants, as well as a "thick" description of findings from the inquiry and discussion about categories and themes that evolved from the data supplied by informants and documents.

Chapter 4

THE FAMILY PERSPECTIVE ON DYING AT HOME

Introduction

The purpose of this chapter is to introduce the reader to 'informants' who over the past two years have allowed the researcher into their lives through times of crisis. The chapter is written in an informal style that best reflects the human qualities of the participants and their stories of living with and caring for a dying person. From the initial period of "living in a pressure cooker" through the difficult stretch of learning to 'do for' and 'be with' a physically deteriorating dying person to the relative calm of the bereavement visit, the researcher was included at various intervals in the lives of seventeen people, seven of whom are considered to be key informants. Alice, the keeper of the diary about her experiences with her dying father, is the eighth key informant and her story is shared in a different way.

Other informants, although not primarily family caregivers, were deeply involved in providing or managing care for a dying person and their stories are helpful in the researcher's desire to understand and to communicate the inevitable "basic social process" of living through the loss of a person for whom one feels a strong attachment.

Data from transcripts are identified by subject number:interview number:page number and field note memos are identified by date. These verbatim data are used to provide the reader with first person information.

Suransky (1982) supports the personal style of "hovering low" over the experience. Suransky (1982:36,37) writes:

> [Theory] must always "hover low" over its grounded actions, over the concreteness of every day experience played out in specific contexts. The immediacy . . . gives us access to the conceptual world beyond which our subjects inhabit but which becomes vacant, devoid of meaning, if divorced from the site and realm of experience and action.
>
> . . . those who begin their enquiries with facts will never arrive at essences. The "fact gathering" psychology . . . produces a fragmented perception of reality precisely because the aim is to gather isolated data from isolated parts of the organism . . . such facts, documented and "verified" will never be more than facts among other facts, facts closed in on themselves, not permitting a grasp of the totality of the human gestalt and resulting in "focalistic vision" that prevents a genuine transforming action on reality.

Suransky (1982) believes that our informants live not only in a physical world of matter and immutable biological laws but also live in a social world ridden with the bewildering complexity of human life. Suransky (1982:30) continues: "To critically intervene in reality, involves seeing the interconnectedness of the personal and social, of class and culture, of history and the present."

Following Suransky's advice, the stories in the study are true to the essence of the experience. Some of the stories are written in descriptive style while others make liberal use of the informants' own words. The style of presentation varies in response to the data themselves and the selection of style is in the service of grounding the description in each informant's unique experience.

The stories are about the personal and social, cultural and historical aspects of the caregiver's life as well as about the caregiving experience. The participants' identities are protected in every possible way, so that although the personalities, characteristics and experiences ring true, the actual detail of these elements may be camouflaged for purposes of confidentiality.

In keeping with the way in which themes and hypotheses developed from the data during the research process, the vignettes (data) are described first and are followed by underlined themes and hypotheses as they surfaced from the caregiver's experience. Reflections on the data are reported as commentary.

We start the narrative by introducing 'Joe' the family caregiver I met first. It was because of the compelling nature of Joe's experience that I continued the research in the role of participant observer and stayed in the field long beyond the initially planned three interviews per family member.

Joe

Joe's 'real' name oddly enough is Dennis. However, Joe is the name that was given to him as a boy and it is impossible to think of him as anything but 'Joe.' Joe is in his fifties, a big man with a booming voice who seems cramped for space no matter where he is. Joe's life experience would read well as a novel and he took great delight in recalling and retelling events and adventures from his colourful life. I enjoyed listening to him and seeing the change in Joe's demeanour. As he talked, he seemed to physically gather strength from the past, strength that may have been useful to him in dealing with the inevitable losses that he was compelled to face. (The power of the story in facing loss)

Joe was brought up in a very strict home by a mother who "ruled the roost." Some of Joe's upbringing reminded me of Allen Wheelis' (1958) story of his harsh childhood in The Quest for Identity. Joe saw a way out by joining the Air Force "too late for action in World War Two" but in time for the Korean War and subsequent United Nations' peacekeeping missions.

Joe's stories and photographs of grain-carrying flights into drought-stricken countries in Africa and his raging anger at the "bureaucrats who were keeping the food from the people" may at first glance be thought of as "dross" and to be taking the researcher away from the caregiving experience. However, as I got to know Joe better, I saw a similar anger at the health care system that was constantly landing him in "hot water" with whomever was in authority.

Joe's reaction to the situation in Africa was to instruct his crew to pour the grain out on the runway so that "the people who were starving and waiting on the edge of the runway could come and scoop it up before the bureaucrats could get their hands on it for the black-market." Joe's reaction to his wife Nan's illness and his disdain for "the bureaucrats who run the system" were running true to form. There was throughout Joe's life, a common thread of anger, even violent reaction, to feeling powerless that was in evidence during his latest encounter with the health care system. Joe was, to put it mildly, perceived as "difficult" by some health care professionals. Joe continues to cut through red tape and fights with anybody who gets in the way even though he might achieve better results more quickly by a little tact. Joe, however, would define 'a little tact' as 'selling out.'

It was, for example, difficult to keep a homemaker on the job at Joe's house due to his moods and expectations. Joe would get thoroughly miffed at the homemaker if artifacts brought home from his world travels were not, after dusting, put back precisely in their places. One day when I visited, Joe was "fit to be tied" because his jug of fermenting wine had been overturned by the "clumsy housekeeper." The judgemental part of me wondered why on earth he would take on yet another project like home-made wine when he was already overloaded with responsibility and worry. We got to talking and I began to see what Joe really needed to get 'mad' at something. It was almost as though he was overloading himself to the breaking point. Anything was better than the shadowy anxiety he was experiencing. Joe is a man of action and used to taking the initiative. This "dying business" was out of his control and feeling helpless was worse than feeling anger or frustration. Joe's reaction may be better understood if it is in fact true, that we tend to fall back on attitudes and actions that got us through other "tight spots" and that anxiety is intolerable for long periods of time. (Coping with crisis: predicting initial reactions) (Anxiety is intolerable)

Joe prides himself on his anger and refusal to "knuckle under to authority." He has no time for "pussyfooting around." After a time in the Air Force, Joe had transferred to Air Canada as a pilot "in charge and responsible for the safety of over two hundred people every time I fly." Joe takes great pride in his work; of being ~~in charge~~. As he puts it, "The cockpit is where I feel most at home, everything in its place. No one gets into the cockpit unless invited in. I don't like distractions and nobody talks back to me there." It could perhaps have been predicted that Joe would have a particularly hard time in coping with the influx of visitors and health care professionals who "invaded" his home "without even knocking on the door." (Lack of privacy a problem in home care: Lack of control over situation)

The other 'invasion' that Joe found hard to take was advice. The one example that Joe gave me had to do with equipment. One of the nurses had suggested that the installation of a hoist in the bathtub would greatly assist Nan's personal care. Joe was indignant. He would have to rearrange the whole unit, take off the shower doors that "cost a fortune." He wouldn't do it. As Joe told me, "It wasn't so much that I minded being told about the hoist but it was just that every time I get advice I have to do something with it. I don't know what's best. I've never been through this before. It all takes energy."

(The stress of decision-making: The strain of taking advice: The need for information)

Joe was already over-run with "stuff." Equipment needed for Nan's care such as an extra large wheel-chair, sick-bed paraphenalia, Nan's books and crafts "all over the house" drove this orderly man to distraction. Frequently when I visited, Joe would be in constant motion, wiping up spills caused by ornery household equipment. Even the coffee pot at first was a menace. Joe, by his own admission, hadn't done much at home before Nan's last illness, except barbecuing and the outside work. Joe attacked domesticity with predictable energy. Nan recalls asking for a peanut butter sandwich and Joe with his usual flair, after a lengthy bout with the kitchen equipment, produced a gourmet open-faced peanut butter sandwich with lettuce trimmings. I wondered as I watched Joe struggle with and master domestic skills if females even in 1986 (when male and female tasks are less clearly differentiated) would find the role of primary family caregiver somewhat easier in this respect than would males, particularly traditional males. (The need to learn or to know domestic skills)

Nan incidentally was amused by the extraordinary effort it took for Joe to produce a peanut butter sandwich. I was beginning to notice that taking on the other person's role seemed particularly difficult while the patient was still mentally able to perform the particular task but was physically unable to actually get the job done. It helped the caregiver to 'do for' the patient when the patient had let go of the task mentally as well as physically or at least pretended to have done so. Sometimes this pretence, this 'biting the tongue' on the part of the patient was, I thought, the patient's way of caregiving to the family. (Reciprocity)

At the time I met Joe, his life was falling apart. Not only was Nan's health deteriorating, but Joe had recently had to declare bankruptcy and move his family from a house with 4,000 square feet of living space into a much smaller house. The final blow was the temporary leave that Joe was forced to take from his work. Joe spoke with contempt about the company policy of grounding its pilots if they seemed to be under too much stress. As Joe said, "I made the mistake of telling personnel about Nan and they wanted to send me to a Psychiatrist." "I wouldn't go so they grounded me." Joe's drastic change in life-style from being away for extended periods to being constantly "underfoot" as Nan called it, was a strain on both Joe and Nan. Nan recalled Marion Pearson's story about ex-Prime Minister Lester Pearson's retirement when Mrs. Pearson had said "I married him for better or for worse but not for lunch." Joe's and Nan's struggle with enforced togetherness made me silently question the well-intentioned policy makers of palliative care who see work-leaves as desirable for primary family caregivers. Perhaps some caregivers would be better left in the Care Managing Role rather than being 'freed' to take on direct patient care. (Care manager vs. care provider)

In spite of bankruptcy and diminished earnings, Joe bought a top-of-the-line stereo system and introduced me to compact laser discs; "the best there are." Sometimes when I visited at Joe's invitiation, I had to ring the buzzer through Sarah Vaughan's or Nana Mouskouri's singing their nostalgic and sentimental songs. The songs played at top volume reverberated through the house and made the first part of the conversation difficult until Joe leaped at the system and tamed the vocalists. (Reaction to multiple losses)

Laurie, Joe's and Nan's primary nurse, who knows them well, had similar experiences when visiting. Laurie, who has worked with dying patients and their families for several years, frequently sees multiple losses that seem to plague the families who are trying to cope with the major crisis of impending death in the family. She was not surprised at Joe's way of flying in the face of loss by acquiring more 'things' even though they were not really affordable. There seems to be a need to take some control somewhere at least on the short term. (Reaction to multiple losses)

Joe's enjoyment of his high-powered stereo system and the romantic nature of his favourite songs were the first signs of his paradoxical nature that became more evident as time went by. As Laurie said, "Joe is really a big gruff Teddy-Bear." On one occasion when both Laurie and I were at Joe's house and he was talking about taking strong actions against the system, Laurie suggested that he was really soft-hearted pretending to be gruff. He smiled as though he had been caught. The need to be the male protector was very real to Joe, a traditional man of the 1950's. (Signs of basic nature/needs of caregiver)

Another example of the need Joe felt to be in charge and the male protector was evident in a time when Joe and Nan reminisced together about their courtship. Nan by the time of this visit was putting up a stiff fight to overcome the cancer that has, to everyone's surprise, still not claimed her. Nan was very uncomfortable sitting with us at the kitchen table but she was obviously enjoying the rare time when they were both happy. Their marriage had been a constant exercise in survival by their own admission. They talked about their initial meeting at an Air Force dance where Nan was being "hassled by another man." Joe came to her rescue. After a very short courtship, Joe and Nan were married and since that time Joe had continued the rather patriarchal role of protector and provider. Joe, in the way he took the role of protector and provider, had much in common with the three other male caregivers-with whom I visited. All caregivers, male and female, became protectors and providers for the dying patient. However, there appeared to be qualitative differences in the way that male and female caregivers worked out their roles and in the way that professional caregivers worked with male and female primary family caregivers. (Caregiver as protector/ provider)

Joe and other male caregivers, appeared to need to bravely tackle the problems head-on and preferably alone. Or, it might better be put that Joe and the other male caregivers needed to act bravely even though they were churning inside. I'll never forget another occasion when Joe, Nan and I were once more at the kitchen table talking about 'the cancer' almost as thought 'it' had it's own presence. They were talking about treatment. "Should Nan go back for more treatment?" They might be able to stop at least some of the pain. 'It' was too far along to be stopped, but some comfort would be worth more time at the hospital. (Cancer phobia)

The conversation swung to what Nan saw as Joe's lack of support during previous treatments. "You never come with me," Nan accused, "How do you think it feels sitting all alone waiting for the verdict?" Joe finally blurted out, "How do you think it feels watching you and those others, no hair, in faded shapeless housecoats that all look the same, shuffling off down the hall?" "It's like being at Auschwitz and I have to stand by and watch! I can't do it."

As I frequently saw happen, the brave façade crumbles for the moment but not for long enough to make a difference. Joe got up and parodied the shuffle. Nan, wounded by the words and parody, said, "But we hurt: it hurts to move." Perhaps I am making excuses for Joe but sometimes there was in his words and behavior a backlash of harshness that was apparently needed to compensate for his sense of helplessness in dealing with this uncontrollable enemy; the cancer, the dying and the innumerable irritations that went along with the experience of watching someone fight to live.

Sometimes it goes differently for caregivers. Other factors come into play. Other factors are found in descriptions of other informants' experiences in caregiving for dying persons and are developed later in this chapter.

Joe, unlike some of the other informants, is not providing constant hands-on care to the dying patient. Joe lifts Nan in and out of the wheel-chair but finds the illness distasteful. Joe in an early interview told me that he believed that the cancer was caused by Nan's carelessness. There seemed, in Joe, a deep need to keep distance from the more intimate physical care required by the weakening cancer patient. Nan, perhaps just as deeply, felt the loss of touch. The psychologist in me wonders if some of the baiting that Nan did, such as leaving a diary out where Joe could see it and read some of the very hurtful things she wrote about him, were not, in fact, ways of engaging Joe in relationship that substituted for the lack of touch she so deeply needed. Straight communication seldom happened and there was increasing frustration and even panic as Nan felt time running out leaving so much "unfinished business." (Working through loss by hands-on care) (Fear of doing hands-on care)

Joe's nature and the increasing difficulty of the situation is such that the brave front seems necessary to maintain at least most of the time. Over the course of two years, I have been a part of high times as well as low times in this family. The high times happen when Joe lets go. For example, a year ago March, I received a call from Nan. Laurie had encouraged her to call Elisabeth Kübler-Ross and see if she could meet with her during her short visit to Edmonton. The answer had been "Yes!" Would I come up and help Joe and her figure out what to say?

Again we three visited. Both Nan and Joe were excited at the prospects of meeting with someone whom they admired and who would surely understand their situation. I have an indelible memory of driving home from this visit that stretched from the planned hour into five hours and thinking to myself that I had been completely unaware of time passing. I felt that I'd somehow stumbled into a place and a space of time-out. Nan forgot her pain and insisted that I stay for lunch. We'd all help. Nan cut up fresh fruit. I cleared the refrigerator and found paté and raw vegetables. Joe used the last two precious bottles of mango juice that a friend had brought back from Hawaii and concocted a delicious creamy drink. There was only a spoonful of rum so we were inebriated on something different.

It seemed that in the midst of all their losses; the pain, the disagreements, the inevitability of Nan's death, that for those few precious hours, nothing mattered. Time out of time. Joe and Nan were on the same 'wavelength.' They met Kübler-Ross the next night. Joe put up with inconveniences that would have driven him "round the bend" at other times. Nan sat, then lay on a stretcher for hours on end oblivious to the pain. They came home and visited with friends "until all hours of the morning."

I received a note from Nan thanking me for a bottle of wine that I'd dropped off on my way home, in reciprocity for the hospitality of the day and also in celebration of the 'high time' that we'd had. The note reads in part:

> We enjoyed your wine while sitting at the 'picknick' table (my bed) at two o'clock in the morning after our meeting with Elisabeth. Four of us talked almost all night. Joe and I are still talking and all goes well and caring. . . .

Kübler-Ross' visit was the catalyst for this period of grace. I have, though, seen similar celebrations and high times for other families as well and it makes me wonder if there isn't something like a gift that is available to people even in the most difficult times of crisis. (Celebration in the face of death) (Communication)

The gift or 'time-out' appears to occur when both the family caregiver and the dying person 'let go' and allow the natural flow of time and events to take precedence over clock time and 'being busy' which may in itself be a paradoxical term. (Time: Chronas vs. Kairos)

The low times are also a part of Joe's story. In fact, part of the low time is not reported in this document as it is judged to be "off the record." However, one such occasion deserves to be told because if the research had progressed the way that I had intended, or if Nan's death had happened at the time everyone thought that it would, this important piece of the caregiver's experience would not be reported.

Nan had decided to go for further treatment, palliative surgery to relieve pressure on her spine. Joe, as usual, visited reluctantly and created quite a stir amongst the hospital staff as he demanded "service" for Nan. I visited after Nan's return home. Everyone was jubilant. It looked as though the surgery had "bought Nan more time." We were all in a celebrating mood. Nan was tired and her friend helped her to bed. Joe and I went to the kitchen to tidy up the cups.

Joe started to wash the cups and over his protests I started to dry them. We worked quietly until he said, "Everyone is happy about Nan's having more time . . . Silence . . . I don't think that I can stand it! Can you imagine how guilty I felt about that?" (Stress becomes strain) (The time of death is impossible to know)

Joe was saying something that may have implications for family caregivers looking after people who are chronically ill. I call it the strain of stress. The family caregiver can provide extraordinary service for a period of time. Energy seems to come to compensate for the stress of providing care on a 24 hour day, seven days a week basis. However, over a prolonged period of time, stress becomes strain and is unhealthy. Stress may be healthy when there is an end in sight even if that end point is the good and appropriate death of the patient. However, the 'it' that Joe was speaking about is "no end in sight." How does the family caregiver parcel out the caregiving; pace himself, when the trajectory of dying has such an uncertain path? (Needing an end-point)

The guilt that follows the surfacing of the well-hidden wish to have 'it' finish is related more to perceived societal pressures than to a lack of feelings on the caregiver's part. I contend that the strain and the concomitant wish to have the caregiving over in due course may be proportional to the sensitivity of the caregiver. Sometimes the suffering of the patient is too much to bear.

Fortunately for Joe, he was allowed to return to work, to the safety and order of his cockpit where he was in control and responsible for a situation that had a definite beginning and an identifiable end.

Nan went in and out of hospital. More chemotherapy was given. I went to visit Nan in hospital two days before Christmas, 1985. She was to be allowed home for Christmas. Their three adult 'children' would be home for Christmas. Maybe it would be all right. Joe was to put up the tree and do the shopping for gifts and the turkey and all the trimmings. This might after all be their last Christmas together.

I remembered a conversation that I'd had earlier with Nan and Marg (Nan's and Joe's older daughter) as they had reminisced about past Christmases and particuarly about Joe's feelings toward family celebrations. Reminiscing with family may be perceived as a waste of the professional's busy time or as an opportunity to better understand the caregiver.

Nan Joe loves to give presents at Christmas time and he loves to shop. He loves to spend money. Who's going to put bonkers on him?

R* Were the things that you remember about Christmas tied in with gifts or was it something else?

Marg** No, I think most because Dad never had much time to spend with us as kids. It was—I think that I do—that it actually was a family and that we did do things together and that he did spend time. This has just dawned on me as I say just a few months ago more so that it was the time that we spent together. As kids, the gifts were always a big deal and everything but—

R Your memories—

Marg The memories are the feeling of us actually getting down together—

R Memory making.

Marg And Dad making us sit on the stairs and even more so, as much as you make things special, it's just because it's so out of character for him.

Nan Yep. He'd make all the kids sit on the stairs—you tell it.

Marg We'd have to get up and make our beds and brush our teeth and wake them up and we could not go downstairs until Mom and Dad were down there sitting in a chair with the fireplace going so they could see our faces when they got in there.

Nan Yeah.

Marg And it was never—it was always, well we'd be sitting there saying can we come yet? Oh, these little kids between the rails [of the staircase].

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*R is the researcher.

**Marg is Margaret, the eldest daughter.

Nan And it was never a matter of everyone diving in and opening their presents. It was a matter of Dad giving us a present and watching while you opened it and you ooed and ahhed and watching your expression.

Marg That's right. We never—everybody opened presents at once. We all watched the one person. It was always—

R So it wasn't—so it wasn't the notion of getting lots and lots of stuff.

Marg No.

Nan It was prolonging it.

Marg We've always like—we've never been the type of people to want to know in advance what we are getting or anything like that. We've always—

R Because you enjoyed the building of the excitement?

Marg Yeah. We'd prolong it as long as we could.

Nan Yeah. . . . stockings.

Marg Stop and have breakfast.

Nan We'd open our stockings which were always fun things and then we'd stop and have breakfast and then we'd—

R Prolong the lovely feelings.

Marg And there'd always be some fun games or something so that we could all sit down and—for a couple of days I think.

Nan Dad and his eggnog.

Marg Yeah. And Dad's never wanted to spend Christmas with other people either because that's when he wants the family. I don't know if I really—we are a close family and yet we're not. That's the way I feel anyway that we're not as close as we could be and yet at Christmas we felt the bond.

Nan Oh yeah, the bond is there. (1:1:73,74,75)

However, this year such a Christmas was not possible. Joe balked. Joe was not able to get "the kids to cooperate." "They just sat." Quarrels ensued, and Nan returned to the hospital early. A low period followed. The next call I had was a request from a counsellor at the hospital. Nan was going home for the week-end and wanted it to work but was in fact fearful of going home. She had asked if I would talk to Joe. (The value in spending time with and listening to the family caregiver)

I went up to Joe's and Nan's home Friday evening after work. At last, they talked and listened to each other. They talked about the pressures of Nan's being home on both of them. Joe talked about feeling like he was unappreciated and unnoticed. As Joe said, "I have to do your work and my work and all people say to me is 'How is Nan?'" I ventured the suggestion that the load needed to be shared. If they wanted help, I would be involved. They would think it over and call me. I left late that Friday night. It had taken about three hours of careful listening to hear each person out. I functioned primarily as an interpreter. (The need for a third person)

It was a cold night that Friday but Joe and Nan insisted on seeing me out to the car. Joe pushed a well-bundled Nan out to the car in her wheelchair. Joe was feeling frisky and the last I saw of them that evening was

Joe pushing Nan's wheelchair up the long driveway. He was pushing her chair very fast and they were both laughing uproariously. (Relief that comes from being heard)

On the way home, I thought, "What a roller coaster and I'm not even on the ride." I received a call from Nan on Sunday. They were having a good weekend. Would I call a few people for her? She wanted to arrange a meeting the following Thursday to see if they could share the load of caregiving and make it easier for Joe. The only way that Nan could have her very expensive medication pump paid for was if she was at home or in an auxiliary hospital. The local hospital would not touch it. The auxiliary hospitals were overbooked so she had to make this work. Home care was her only alternative if she wanted to continue with the medication pump. (The dilemma of science being ahead of services) Nan was taking control for herself and Joe was cooperating. I agreed to help arrange a meeting for Thursday night. (The patient and the family in charge of the health care team)

In the meantime, I had received a call from an administrator at the acute care setting advising me that they could not send a counsellor or representative to the meeting. The meeting was held. I made my position clear, because I felt that it was necessary. Even though I was there at the patient's and the family's request, I was perhaps overstepping my boundaries as researcher. I would function as chairman for the evening. I somehow felt that it was necessary to read from prepared notes that stated, "In hospice care, we believe that the patient and the family are at the centre of care and that we professionals and volunteers are to fit ourselves in to the wishes of the family." (Role uncertain due to territorial concerns)

Each person introduced him or herself. In attendance were Nan, Joe, their daughter Joanne, Nan's best friend, another friend who is a retired nurse, the retired nurse's daughter, Laurie, the primary home care nurse, and the Supervisor of the Homemakers Program at SHU. The doctor, who was supportive and could be counted on to make home visits as required, was unable to attend the meeting called at such short notice. (Sharing the load: The need to plan)

The results of the evening were rewarding. It fell into place "just like it says in the hospice textbook" I thought to myself. The division of responsibility was spelled out. Nan and Joe talked about their needs and each person present took a piece of the responsibility. Laurie would resume her daily visits; a homemaker would be put in for four hours a day; the retired nurse would come in and assist with the medication pump; her daughter would move in to the empty downstairs suite and be a companion for Nan while Joe was away. Nan's best friend would be relieved of her constant need to be there and could visit at will. Nan was finally functioning like "the chatelaine of my castle" which was her dream. As she had told me previously, "I only die once. I want to get it right."

There were two hitches. Nan's best friend looked uneasy and finally spoke up and said that things were not "that good." There was, she said, unresolved tension between Joe and his daughter. What could be done about that? After some discussion it was resolved that Joanne and Joe would go for counselling in an attempt to establish communication and to repair and rebuild their relationship.

The second hitch came as a surprise. This meeting was not a planning meeting but was the real thing. Nan had been discharged that day. She was home. The meeting was not a rehearsal. The plan went into effect the next day. (The need for communication between the acute care setting and home care or community setting)

The hospice style of home care in which work is shared by many to prevent strain on any one individual was successful on the short term. It seemed that Nan and Joe were able to 'let go' of some of their responsibility and were relieved. Nan was feeling more secure with a companion in the house.

Nan had been doing her reading and the one place she felt she would be able to "die right" was in the Palliative Care Unit (PCU) in the City. Fortunately, Laurie had arranged for a place for, or at a minimum, a consultation when Nan's condition warranted the PCU's limited space and stretched resources. Nan and her friend made a trip to the PCU and spent some time looking around and visiting with staff and patients. Rather than feeling depressed at the prospects of ending up like the patients in the very last stages of dying, Nan seem buoyed up by her visit. (Patient's need to secure a safe place for death)

Nan had a short reprieve from her struggle. Later, there were complications. Nan got an infection under her medication pump that started at the "size of a quarter and became the size of a dollar bill," as Joe described it. (The use of metaphor may be instructive) Nan had to go to hospital to get the infection under control.

Laurie called me in July, 1986, with the information that Nan had left Joe and had moved into an apartment in the city. When Nan had been discharged from the hospital she was well enough to go to Ontario to visit with her daughter who was having their first grandchild. Nan planned to come back to the city apartment and live out her life there with her friends' help. She had given up trying to make Joe into the caregiver she knew she would need in the future.

Joe is working hard trying to make order of his life.

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I called Laurie and asked her how Joe and Nan were doing. She said that she had heard second-hand that they were still not living together but that they had been seen together in the Mall. I said that I had not called lately either. I think that we are both reluctant to become embroiled once more in the chaotic, larger than life drama that is the dying process of Nan, and the experience of Joe as her primary family caregiver.

The one thing that seems very clear is that at least for Nan and Joe the trajectory of dying is not a clear, smooth arc but is rather more like a line left by a roller coaster. The ups and downs and twists and turns that Nan's and Joe's lives take as they struggle to 'let go' are exhausting for the professional caregiver who becomes involved. Apparently Home To Die does not necessarily mean an easy Death with Dignity. There are, as I was learning, many factors that complicate the 'process.'

Salim

Introduction

Salim's story is a case-in-point. Joe and Salim are about the same age, both male caregivers to wives dying of cancer. My time spent with Salim was shorter, more formal, partly because of Salim's more reserved nature and partly because Nadia, his wife, died within weeks of the start of the inquiry. My research role stayed, for the most part, within the boundaries of the interview. Even so, the unique qualities of Salim's experience will, I believe, be seen through the restrictions of time and place.

Language is another potential obstacle to understanding Salim's experience. English is Salim's second language. Transcripts are used copiously because Salim's own words are the best way of telling his experience. However, on the advice of two of the readers requested to critique this document, the transcripts have been edited slightly to make them more readable.

The people I met through Salim's caregiving experience are:

Salim: 42 years old, born in the Middle East, professional engineer (Ph.D.).

Nadia: 32 years old, born in the Middle East, professional engineer, dying of ovarian cancer which was diagnosed during pregnancy with Ellen. Nadia died September 21, 1984.

Joel: 2 1/2 years old, son.

Ellen: 1 year old, daughter. Born by Caesarian Section six weeks prematurely due to Nadia's ovarian cancer.

Colleen: Homemaker who worked days. Had been with the family for over a year.

Laurie: The home care nurse.

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September 21, 1986 was the second anniversary of Nadia's death. Laurie and I talked about the progress Salim is making in comparison with the difficulties that are being experienced by Joe and Nan.

Laurie told me that she had seen Salim a couple of weeks ago "at the community fair" and that he looked "terrific." "He's grown a beard!" "Do you remember how reserved he used to be?" Laurie asked. "Well now, whenever I see him he gives me a big hug. The kids were with him. They were riding those little motorized trikes and Ellen (the baby) was terrorizing the population riding in all directions and Salim if you could imagine was laughing at the antics."

I had been visiting, or more accurately, interviewing Salim at the same time that I was visiting Joe. It was interesting to hear about Salim and to reflect not only on the differences between them but also on the changes in Salim's appearance and personality.

Salim had done well after Nadia's death. I felt as though I'd come to know him even though I had spent less time with him than I had with Joe. I had been in contact with Salim beyond the planned 'closure' of the bereavement visit. For a couple of months after Nadia's death we tried to find ways and means to free up Nadia's hospital chart so that Salim could "go away by myself and read about how she had really died."

Salim is persistent by nature and methodical by training but felt frustrated with his attempts to get his hands on the chart even though it was his legal right to do so. The administration didn't say "No" outright but he felt that he was getting "the runaround." The administration thought that he should have a doctor there to explain the terminology to him. I suspect that this precaution was to protect him from the pain of knowing about the last few days of Nadia's treatment and life. There is a certain irony here when one considers the facts about Salim. (Health care system's desire to protect)*

Salim had, in fact, cared for Nadia at home up until two weeks before her death when she finally insisted on going back to hospital "to get my blood straightened out" as she told Salim.

I was with Laurie when Nadia was getting ready to go back to hospital. Although Nadia was very weak and thin, she insisted on supervising the packing of her suitcase. Laurie and I acted as props as she made her way up the stairs for, as it turned out, the last time. Nadia confided that it was just getting to be "too much." I didn't think to ask "too much for whom?" It wasn't the first time that I'd noticed the patient take control while the rest of us were rather overwhelmed, a bit stunned by what was happening, and I suppose just glad to follow orders and have something to do. (The patient lives the dying process: Others can only imagine it)

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*The grammatical 'error' of personalizing a non-person is intended.

Perhaps Nadia meant "too much for Salim to manage." Salim worked as a professional engineer for a large company in the city. Salim and Nadia had two small children, Joel a two and one half year old boy and Ellen who was one year old. Nadia was looked after during the day by a homemaker who was "put in" as part of the new palliative care program at SHU. The household was certainly active. One day when I visited, Joel had just thrown his tricycle against the glass patio doors and the homemaker, looking a bit frazzled, was trying to convince Joel that he would feel better if he "would just have a little nap with his sister." That was the day that the researcher "was helping a homemaker fold socks while hearing about her fears and responsibilities" (p. 85).

Salim came home about 5:30 every night. The homemaker left when Salim came home. Until 7:30 a.m. the next morning, Salim was "in charge" of the household and Nadia's care.

Again, it seems necessary to describe Salim. Salim is a tall man, heavy set, always well groomed and physically fit. "I work at it. Or at least I used to work at it.

It's one thing I miss a lot. I don't have the energy anymore to even go for my noon hour walks," Salim told me during one of our interviews.

Salim had been born in the Middle East. The features that I remember most are his very serious dark brown eyes behind horn-rimmed glasses and his closely cropped black hair that at forty-two was just beginning to gray.

Salim had come to Canada to take a degree in engineering. He took his undergraduate education in Montreal and his graduate training (Masters and Ph.D.) in Ontario. During his "young days when I was crazy" as he described it, he had married another engineering student. A short childless marriage ended in divorce.

During this same period of time Salim's mother back home died very suddenly. His father became very ill and wrote to Salim begging him to come home at least to visit. Salim said to me: "I can't imagine now what kept me from going home but I figured I was too busy. My father died too without my seeing him. My advisor [in graduate school] told me that he didn't know how I did so well with all of this happening." "Of course I wasn't cracking up," Salim told me, "but I was feeling it inside." (Reaction to multiple losses) (Coping with crisis: Predictable initial reactions)

Salim came to Alberta to make a fresh start. He very soon met Nadia who was "a beauty," settled down and had two children "very close together. I wasn't getting any younger." Salim took me into the living room to see their wedding pictures. Nadia was "a beauty." The difference in Nadia's appearance was startling. Cancer and the battle she was fighting with 'it' had taken their toll over the past few months. "Amazing," Salim said as we looked at the picture, "because really all plans have been shot down."

Salim summed up his experiences this way:

> So, you know, things were not all the time that rosy in a way. But . . . actually, nothing can really compare with what's happening now. . . . I mean, it's really much worse than anything like—losing my parents, they were old age, eh? The other thing . . . no children out of the [first] marriage, nothing you know and you're young and after a year of so you are back in another relationship—there is nothing like what's happening now—it will have a life-time effect. (Coping with wife's dying the greatest stress) (2:1:29)

Nadia had been diagnosed as having ovarian cancer. Its 'trajectory' is usually short and they say relatively painless. Salim talked about the changes in Nadia's and his own feelings over the past few months.

> Salim Maybe some time ago I was a little bit—when things were not quite—they were vague, you know. Is she going to be cured, is she going to be—going to have chemotherapy? You know, rides to the hospitals two, three times to meet the doctors—[He] answers maybe the first question . . . first concern [only]. So things were very mobile and very uncertain.
>
> But once you got the news—of course, it's shock in the beginning. Like we just cried

a few times. It takes some time to sink in.

And that you just accept—accept the fact. And I think even my wife herself, like, she's maybe reached a peace with herself. Although we don't really speak as—say that you speak about the whole thing. We don't really—we have not spoken about her death. The topic has been avoided. Or just passing by very quickly. It's not like what you read in other books, you know. That's one thing that we have not been able to do. (Family members don't talk about dying).

But she may be accepting herself what's happening and maybe the same thing applies to me too that I do now—I know it's happening and I cannot do anything about it. I'm just helpless.

R And you help where you can and do what you can do.

Salim Right. Yes. But then, the final—the sentence is passed. We are going through the trial now, like there's no suspense. (Relief from anxiety of unknown) (2:1:6,7)

After a pause Salim continued:

Salim One thing that—I don't know if I want to say that on tape—but anyway—

R If you would prefer—

Salim No, no, no. That's okay. In a way, I was never that religious a person and that thing did not really reinforce—actually it reinforced me in not being so religious. I think it's an unfair thing to happen. So, on the other hand, with Nadia, she is really getting more of belief—like, a few times we'll sit and talk and some of my words reflect maybe anger or unacceptance—

R Yes.

Salim Of, you know, of what's happening. She says no, no, don't lose your faith and all this kind of stuff. So with her—

R It's deepening her faith?

Salim Yeah. Yeah. Although with me, you know, it was not strong to start with . . . and it's not helping either. Is going away from me now. So that's—a reflection of what's happening. (Patient and family at odds in their beliefs) (Reluctance to speak of spiritual dimensions) (2:1:7,8)

Although Salim had been in Canada for sixteen years there was an unmistakable accent to his voice that, along with his appearance, almost trapped me into believing the 'literature' rather than what I was seeing with my own eyes. People from Middle Eastern cultures are, it is thought, much more likely to be "in touch with their emotions" than are North Americans. Salim "should" be expressing more emotion. That may be so. Salim had, in fact, sent his father-in-law, who had come to ~~help,~~ help, back home because "he was too broken up." He had, in fact, become "a burden" to the family rather than a help. However, Salim looked to me to be steady and doing what he needed to do in order to keep going. (Need to avoid cultural stereotyping)

Salim described the differences in people's reactions to crisis and Nadia's dying:

Salim I think different people can handle a situation like this differently. Like her father, for instance, who loves her very much definitely, no doubt, was visiting us, so was her brother and her sister, but her father stayed the longest time. And I can see that he could not actually handle the situation. He was bursting in tears quite often and we talked about it and we decided it maybe best for him to leave.

R It was too much for him to see?

Salim It was too much for him to handle and, you know, we were concerned about his health too because he's in the sixties now and being unable to cope with that. Actually I've been classified by friends that I'm a strong person and I think maybe I am because going through—that's not the first bad experience in my life—I have had a few before, but I think I do handle stress maybe better than other people that I've seen. Maybe that's why I can—I don't mind to be around, close to her and I don't mind to be seeing things like what's been happening. So, although it hurts, you know, I think I can cope with it. I am coping up 'til now, at least. (2:1:5)

Like to be very honest with you I think if I—if I had a choice, I would prefer if I would be the one to go. Not Nadia. Because it's much better for everybody—like losing the mother is really terrible. You know I just can't—terrible for the children and for the husband. Like, a husband—it is very hard for the husband to raise children. (People have different fears and strengths but not culturally based) (2:1:30)

On another occasion Salim and I talked about cultural differences in response to crisis. It seemed important to understand because many family caregivers are from other countries. Quotations are again from the transcripts.

Salim . . . for men, maybe they are not [pause] they are supposed to be the strong, the strongest piece in the homo sapiens or something. Supposed not to be the crying type and no one's supposed to cry. That's actually—I think it is a global thing more or less. .

R Oh, so it's not just North American.

Salim No, it's a global—actually, maybe in our culture [Middle East], it's more maybe. It's more stressed that men are not—

R They're to be the head?

Salim Are not to cry. Yeah. You know, they're supposed to be the ones that can handle the situation without like—One time we met Dr. D________, you know, and Dr. ________ and both were psychologists. Anyway, we were talking and [Dr. D________] was concerned about Nadia because she was depressed and stuff like that and he was again telling about how to cry and all that and don't hold back. But still, it's easy to say—You hear and read things how it's supposed to be done. I'm not doing it, you know, that way either for myself or even during or after, during the illness or after, after Nadia's, you know, I'm not doing it according to the book. (The strain of taking advice) (Avoid saying the word 'death')

Like everybody says, suppose or not suppose—you can do this, you can do that, but it doesn't come to me, just because I read the book, I feel that I have to—. . . [pause] We had a couple of long discussions with Dr. D________ and he being from my country too. So he seems to understand things of the culture huh.

But again, even Nadia and I we talked about after that, things we agree and some things we don't agree with what he said.

R Uh hum. Because you're an individual even within the culture.

Salim Yeah. Yeah. (Each individual is unique) (2:3:14,15)

I remember Joe's taking exception at being sent to a psychiatrist for stress related behavior and Salim's and Nadia's confusion at advice on how to deal with this crisis and wondered how the 'System' could have better helped them.

Salim, like Joe, had found out about Home Care in round-about ways. Joe had been alerted to the possibility of receiving professional home help by a neighbour. Salim had been told by "social services" at the acute care hospital in the city that he would qualify for home help. However, linkages had not been made for him and he found himself in a panic on the day before Nadia was to come home. As Salim tells it:

> I didn't know what to—they told me, okay, there's something called homemaking service. I never heard about any of this stuff before. So I was—so many people were coming to be very nice in the hospital, eh, social service and I was getting information from them. They say, okay, no problem. You'll get homemaking service when your wife goes home because she will be unable to look after Ellen and the other child and they assured me everything would be fine and dandy. So it's okay, it's a matter of—you know, who should I contact to make sure that . . . the person's coming in time, because Nadia was coming tomorrow, out from hospital and I have to make arrangements for somebody to be with them. (2:1:21)

When Salim phoned for help he found that he was not qualified for homecare. Salim continues:

> A few hours later I got a call back—I'm not qualified for the homemaking service. It was mixed up and was a mistake—and no, you are not qualified. So can I come and meet? . . . I went downtown. She showed me a regulation of the government that because my wife does not have a dressing—she does not require a nurse to come so she cannot—I was a little bit . . . Nadia was coming out the next day—I didn't know what to do.
>
> It's been difficult, it's been very difficult and it may be, it may be coming to even a little bit more of a crunch. (The need for information) (2:1:22)

Salim had been fortunate. Rules were stretched by Mrs. B________, the Homemaker Supervisor at SHU. A homemaker, Colleen, was "put in." As Salim says:

> [Colleen's] been with us almost all the time except odd times when she was busy or sick or something. Somebody else from the service also came to help. So the service is superb and it just adds the nicest touch because she is concerned also. And you know, Mrs. B________ was really very supportive because the service is supposed to be an emergency type thing and supposed not to be for a long time like this. So she understood the situation and although she encouraged me to look for somebody else and I've been trying, putting an ad in the paper and this kind of stuff to find somebody most responsible. (Bending the rules)
>
> I ultimately figured I'll try one—that seems, you know, all right. And she started actually last month with us for only five-six days and she could not cope with it and she came to me and said she found it very difficult to cope with the situation. It's too much for her. (Home care a difficult job)
>
> So I got back to Mrs. B________ and explained the situation. I managed to get Colleen back again the following day. So this way it is very good. Although still the same thing may be happening again. Colleen is going on holiday the beginning of next month. (Difficult for caregiver to find own help) (2:1:8,9)

Salim So that's why I have to have somebody at home and even I hinted to Mrs. B________ at one time that I would appreciate if I can get a green light that, you know, I won't be looking for anything 'til things happen with Nadia.

R Yes.

Salim You know what I mean.

R Yes.

Salim She could not really give me that assurance. Because maybe that's—maybe Nadia would be in and out for six months, maybe a year, you never know so for her maybe that goes against

> the regulation or the criteria that they work with, eh. (Pressure caused by uncertainty)
>
> [It is] hard to accept—it's hard to say okay for this person, okay you are sick and all that—you'd better die within three months, otherwise, you know, you are off the emergency classification. (2:1:10)

Salim talked about what he called his "juggling act." He was, when I was visiting him, trying to keep things going at home and at work.

Salim	If I have to go and depend on young children [to babysit] or something, I don't know what would be happening. It would be a lot of stress on me. I don't know how I could handle it.
R	Half your mind would be—
Salim	So that's one thing I don't really worry about when I'm at work.
R	But you're saying how much more helpful it would be if you could be assured, if you could relax on that point.
Salim	Yeah and I know that at least I don't have to think, I don't have to subconsciously think okay, I wish my wife dies within three months, otherwise I don't know what will happen, you know. You know what I mean? (2:1:12)

The really impressive information was that Salim was able to administer TPN (Total Parenteral Nutrition) to Nadia. TPN is a relatively sophisticated method of feeding that requires the caregiver, usually professional, to attach an intravenous bag and tubing to a catheter that is inserted into the Superior Vena Cava (a major blood vessel). The catheter remains in the patient.

The home care nurse, gloved and gowned, did the sterile dressing that was required. However, Salim had, every night for a month, with his engineer's precision, carefully hooked Nadia up to her "machine" as Salim called the TPN apparatus. Nadia had been the only patient in the home care nurse's memory who had been fed at home this way. Salim, however, did not think he was doing anything exceptional.

Salim told me that "It's not really that difficult, although I was apprehensive at first. . . . if she needs only TPN care . . . maybe she vomits once in a while and stuff like that . . . I can look after this" (2:1:2). Salim told me that he helped Nadia in and out of bed, helped her to the bathroom and helped her with personal care. "It is nothing." (Each 'case' has unique features) (Home care professionals and lay caregivers do nursing care)

My admiration for the inventiveness of the home care nurse grew as I kept in touch with Laurie over two years and heard from her and from other home care nurses about their palliative care patients and their various and complex needs.

I was told that not all primary family caregivers are as reliable or perhaps a better word would be as courageous as Salim. One of the home care nurses at another unit had taught a family caregiver how to do a colostomy dressing for his terminally ill wife who had recently returned home from hospital. The nurse was unable to get back for three days. She phoned to see how they were doing. "Fine" she was told. Three days later she found that the colostomy dressing had not been touched.

Understandable reluctance on the part of the family caregiver to do some of the more difficult treatments may be a problem for the professional nurse who can only be in each home a short period of time.

Salim was a particular favourite of the home care team I was involved with, partly because of his courage, partly because of the two children, and partly because Nadia at thirty two was "too young to die." It was all grossly unfair. Colleen, Salim's homemaker, would often work "a bit extra" on her own time just to help out. I had been impressed by the homemakers, these "substitute" primary family caregivers and decided to spend some time with Colleen.

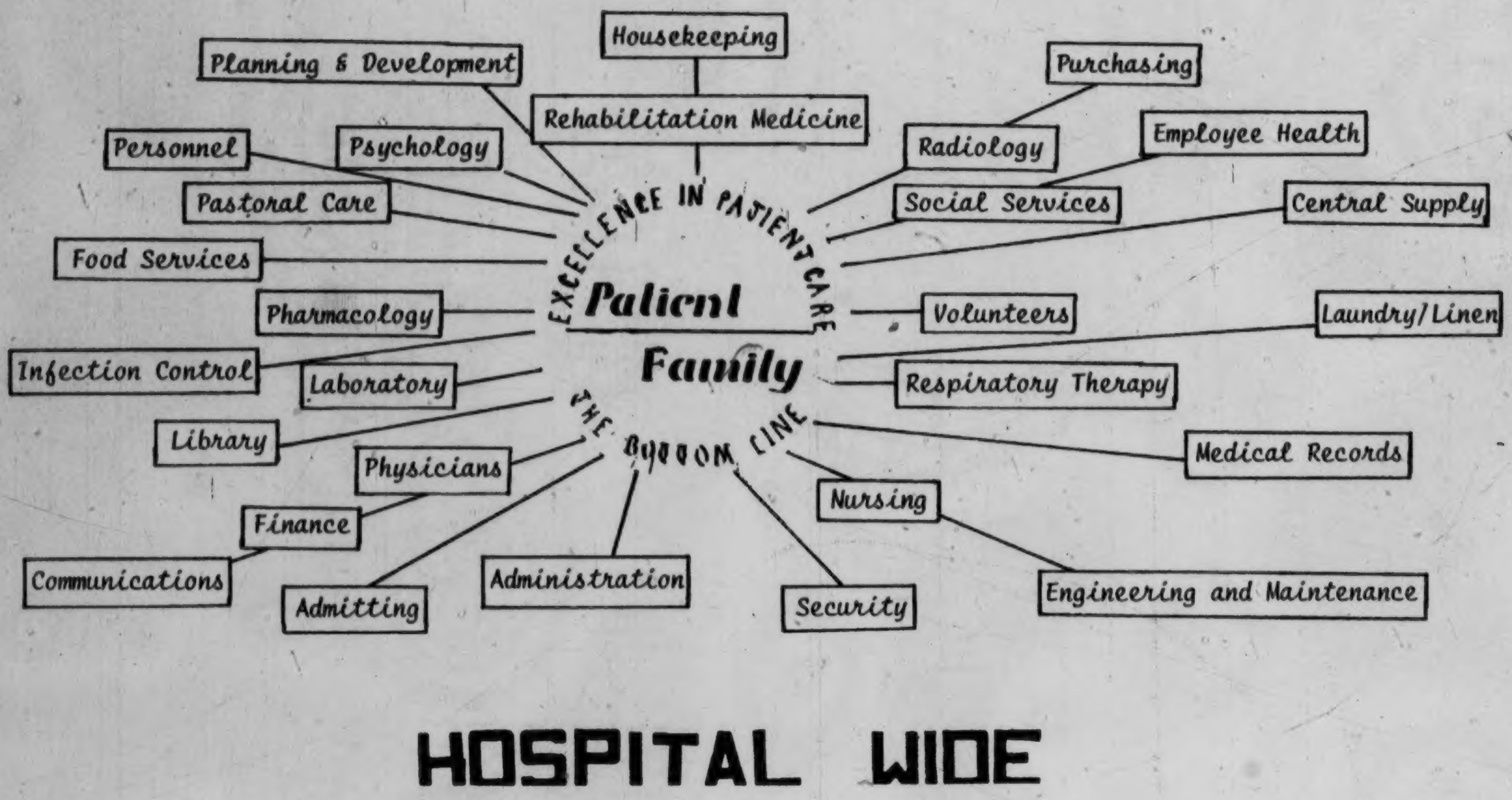
Colleen is Irish, middle-aged and a "strong Catholic." She feels her work is "just doing my bit." At the time I interviewed her she was planning a trip "home" to Ireland and looking forward to "getting away for a while." Colleen admitted to feeling somewhat queasy about working with someone who is as "sick as poor Nadia." "Sometimes my stomach turns upside down when she gets so sick." (Identifying with patient leads to compassiate care but also fatigue)

Colleen thought that "past experience as a mother" prepared her for her job and that it was her "faith that gets me up in the morning and out to the bus winter and summer." "It's not too bad now," she said, "but wait until December when I have to come and go in the dark."

Again I was impressed by the ability and the dedication of relatively untrained primary caregivers who looked after patients who were exceedingly ill by anyone's standards. A physician who works full time with palliative care patients told me that patients are becoming more difficult to care for at the 'terminal' stage. There are a multitude of treatments and surgeries possible to treat cancer. Patients and their families naturally want to try whatever may delay death. Therefore, by the time patients reach hospice care, they are very weak. (Difficult to care for 'terminal' patients)

Caregiving for very ill patients brings to mind a pictorial grid of hospital services that was posted in a local urban hospital during the hospital's annual Open House. The poster depicted the hospital's patient and family surrounded by batteries of service providers. The diagram is used with the permission of the artist.

It struck me when I saw the graph on the hospital walls how different a diagram of home care services would look particularly before the Palliative Care Programs were in place. Although the Government of Alberta in 1984 had


Housekeeping
Planning & Development
Rehabilitation Medicine
Purchasing
Radiology
Employee Health
Personnel
Psychology
Pastoral Care
Social Services
Central Supply
Food Services
EXCELLENCE IN PATIENT CARE
Patient
Family
THE BOTTOM LINE
Pharmacology
Volunteers
Laundry/Linen
Infection Control
Laboratory
Respiratory Therapy
Library
Medical Records
Physicians
Nursing
Finance
Communications
Admitting
Administration
Security
Engineering and Maintenance
HOSPITAL WIDE

Acute Care Hospital's Team of Care Providers set aside one million dollars for Palliative Home Care, the one million dollars was to be spread across the province. In keeping with the autonomy built into the Alberta system, there would be variations in service depending on the community in which the patient and caregiver lived.

Salim had heard rumours about the potential for change in service but needed more information. He had a dying wife and two children to care for, for an indeterminate amount of time. Salim fished for information:

> Salim At one time there was something in the budget mentioned about extending the homemaking service and the nursing at home?
>
> R Yes
>
> Salim One time I only mentioned it to Laurie— Do we qualify for this for not?
>
> R Yes?
>
> Salim She said, No, the rules were not known yet and the government was going through so many considerations. It boils down, it will be different rules for every county and every jurisdiction. It would be better if I know that maybe I can get, but I don't even want to push the point because I just am happy with—I'm paying a certain amount, although there's maybe something I could make use of but I haven't.
>
> . . . right now maybe it is the case we can't even officially [qualify] because according to Mrs. B________ I am financially a burden on her. . . . Although if the province comes in my understanding is that while I am on homemaking service . . . Mrs. B________ would be paid by the social service. (2:1:14)

It was a dilemma for Salim. His businessman/engineer's mind struggled with the practicalities of meeting the budget. Budgets were familiar to him. However, his need for service particularly Joel's and Ellen's needs were first and foremost and he quite naturally, I believe, lobbied Laurie and Mrs. B_______ for as much help as possible.

Salim, as was previously mentioned, is a methodical and practical man and after an initial fight with SHU administration over "lack of services" had put his energy to learning other "survival" skills. By the time I got to know him the new palliative care program had started and there was funding available to provide a homemaker to look after the children while he worked. The children he said were his major concern. Colleen the homemaker always left "supper just about ready" and he was able to assist Nadia and the children to settle for the night.

It was not quite as easy as it sounded. Ellen still needed a 2:00 a.m. bottle and Joel tended to have bad dreams and "call out in the night." Salim was worried that Joel had reverted to "the bottle" again. Salim described what was happening with Joel:

> Salim I think he senses something. Because mommy's not home and she's throwing up quite often and she gets hooked to this machine every night and all this kind of stuff. He feels that something different is happening to her. And although he's not sad . . . there's no sign of sadness. Although maybe it's reflected

in his behavior a bit. Like at times he behaves spoiled, he nags—not nags, what do you call it?

R Wants a bit more attention?

Salim Yes. Whines quite a bit actually and tries to get his way by whining or by crying. He used to be—I put him in his bed when he was less than a year old and he'd never complain about that. Now he gets up quite often during the night and he cries and I try to calm him down and the only way I take him, you know, with me, [to bed]. And he's calm and he sleeps.

I try to force myself not to do it but, you know, still the soft spot. I leave him and try to ignore him but there's no way so maybe I'm not strong with him. I maybe developed the habit now that I can expect almost every other night or every night he cries in the mid-night when he wakes up and I take him with me. Although I want to break it, I couldn't so far. His toilet training is a worry. Up to now, he's two and a half, and still not toilet trained at all.

So, I don't know if what's happening is affecting his behavior in some aspects or not, I'm not really sure.

R [getting involved] Um hum. It must be a temptation to give him comfort where you can though.

Salim Yeah. Yeah.

R With a bit of security of knowing he can come in with you.

Salim Yes. When Nadia was in the hospital some time ago, she was there for almost three months or four months continuously—and I used to take them once a week because she was not really that bad at that time. So he even realized that, after some time, whenever I was still in the street before turning into the parking lot—he said, mommy, mommy. He realized it was the hospital. So definitely he, you know [pause].

R He's taking a lot in.

Salim Yes.

After a pause Salim continues:

Salim Once in a while now, he . . . goes to the . . . to the closet and holds one of her dresses—"That's mommy?" Well . . . he mentions every name to what this piece of clothes belong to. I think they say kids less than six years they won't—it won't sink in, you know, for ever. Like— [pause]

After some time they may not really feel, feel—

Except that you know they start realizing that they are going through life without mother.

R It must just be kind of confusing for them now.

Salim Yeah. What's happening—

R What's happening and sometimes mom's here and sometimes she's not.

Salim Yeah. Exactly. (2:1:17,18,19)

Reflections on Process

It was becoming hard not to get involved. There seemed to be an obligation in hearing the story in the context of its happening—I could too easily visualize the 'actors' and feel the differences between our status. Here was I like Avorn (1984) described, on my cabin cruiser circling the victims and supposing that all it took to do this research was to inquire into the family caregiving experience and leave with the data.

Perhaps that stance could have been rationalized. Intervention would distort the findings. Better to get the real facts of the caregiving situation no matter how distressing, write them up so that the "many" could be better served.

I don't want to make the interventions I found myself making sound heroic in any sense. The interventions were relatively easy—more in line with finding someone else to throw a life-saver over to the 'victim' rather than on the order of jumping into deep water myself. However, to mix metaphors, while in the field I was aware that I was siding very definitely with "the natives." Academia and the writing of the dissertation seemed light years away even though I was memoing like mad.

I was beginning to appreciate the difficult position of the primary home care nurse. She goes into the home, sees the people, helps then moves on to her next patient. As the nurses told me, they don't have time to sit down and listen to the family caregiver as much as they would like to. The physical care of many patients had to be done. There was a certain amount of frustration.

Each home care unit is, of course, different. Each nurse is different. Laurie tended to get involved and get caught in the "psycho-social" processes as well. Our weekly sessions usually ended up in problem-solving. As Salim said, nurses needed "the technique" but it was also important to know that they cared about his situation. I found myself rearranging the evaluation framework that

I was working on for this study. The data were having their effect.

Salim taught me a lesson about appropriate amounts of involvement that are instructive to this inquiry. Salim was obviously worried about his children. After Nadia was re-hospitalized he was really in a bind. He needed to be in two places at once. There were commitments at home. The homemaker would stay beyond her officially allotted time, it was true, but there were weekends to cover. Friends were not quite as available to babysit as they were at first. Even in this relatively short 'trajectory' of Nadia's dying, people were wearing down. Then there was Nadia, in the hospital, dying now for sure although they still hadn't actually talked about it. He needed to be with her more than was now possible.

The logistics were really impossible. Salim lived 45 minutes away from work in the city. Nadia was in the city hospital. To visit in the evening, Salim had to drive 45 minutes back home, feed the children, find a babysitter, then drive back to the city, sit with Nadia for a while then drive back home. He was able to get over in the lunch hour for a few minutes but without family here, he was, he felt, her only source of support. Things had been a lot easier when she was at home even though, as he said, it was a "trade-off."

Sometimes I was surprised at how this very emotional time of watching someone die became a very practical exercise in logistics. As Salim said, "every five minutes is accounted for." "You wouldn't believe how I have to think about every minute, where it's spent."

Salim was also beginning to fret about his car. Winter was coming. He had not been able to get out to get the tires fixed and the fall tune-up done. What if the car let him down somewhere between home and the city? And the bills, he hadn't gotten to them lately. He used to pay the bills while he was out for his noon-hour walk. He liked to plan ahead, keep on top of these things. As he said, he felt as though he was living in a "pressure cooker"; sometimes it simmered but sometimes "it boils over" like now. "You know, if anything unusual happens it would be a disaster. I won't know how to deal with it."

In the back of his mind always was his need to be with Nadia to protect her at a time when she needed him most—and the children—what was all of this doing to them? (Multiple stresses: The practical side of caregiving) Salim said to me, "Sometimes it feels like I'm just sitting and seeing a bad movie going in front of me." (The use of metaphor)

He talked some more along this line—about not really "being there."

Salim . . . actually so many times [at work] I go to the coffee room and the guys are sitting and I'm just listening to them but I don't participate, you know, I'm just watching things . . . I don't want to participate because I cannot contribute. [The way I feel about Nadia] is reflected for me at work too. I just sit and . . . maybe they talk and actually I enjoy . . . it's not really enjoyment but I just—I go there you know. . . . I do not reach the complete isolation thing [yet]. (2:1:24)

Salim continues:

Salim Yeah. But to be honest with you, I start feeling that things may be starting to be getting to me now. Maybe at the beginning I was a little bit emotional about things . . . I was just living day to day and doing things as they come but maybe now they are start getting to me. I'm not the person I used to be a year ago. . . . like even at the office . . . I did change quite a bit. (2:1:23)

After a lengthy pause and some other "puzzling" over the change in his behaviour he continues:

Salim I just find it is really getting to me and I—somehow I feel like [pause] I really want to do something, something for Nadia, but my hands are tied. I wish I can go and spend some time with her more than I am doing now.

At the beginning it was not so bad and she was maybe more occupied—her family was here, friends were more concerned going to see her. Now things are old for her. If she's home . . . I feel that if she's home—I wish she's home actually. Because I think if she's home she has company.

R You'll be together.

Salim She is neglected now and my hands are tied. I was writing to my brother. I wish I could send the kids to you now because I know they are the thing that is keeping me from going and seeing Nadia more often. I know she feels isolated very much because, besides this hour at lunch, or even half an hour for that matter, she is there by herself all the time, thinking and maybe—well I just don't—

R It would just be good to be with her.

Salim Yeah. Especially if these are her last days. I just feel that I want to be there more than I am doing but I— (2:1:25)

Nadia had been admitted to hospital and Salim was torn between his duties to his children and Nadia. We wondered about getting more help for Salim. Laurie had heard about a group just starting in a local church. They were interested in helping out in the community. I said I would check it out. It didn't take long. They sounded well organized and although there were all sorts of possible repercussions that went through my mind, I decided to make the connections.

The church volunteers were not trained, not covered by any insurance. "What if one of them fell?" I stopped thinking and acted on instinct. Salim welcomed the help that appeared almost instantly on his doorstep. As he told me:

> To have this extra hour to spend with Nadia in the evening . . . I don't feel that I have to rush . . . to be able to find [someone] to spend that couple of hours. I really appreciate it. . . . like I was telling you on the phone. Very quick and very good.
>
> . . . to think of a person who does not know you, come and spend whatever time—time is precious for anybody I think—so for them to come and spend a couple of hours in the day . . . doing that . . . I appreciate . . . because it's different than if a person you know is doing this for you because of the relation but a complete stranger offering you this is very touching. (2:2:3)

Salim continues:

> [The volunteer] . . . even came on Saturday and spent three hours with the kids. She was saying . . . she was contacting people and describing [the need] to them . . . I don't really belong to the congregation, but still with, even with this, people come all the time and really help. (2:2:3)

The volunteer help was sounding really good and it was. However, later I was beginning to hear another message.

> [The volunteer] actually made arrangements for the weekend . . . to have solid every day. [I told her] . . . you really don't have to do this. Even a couple of evenings a week . . . because you know, you don't really [want to] overburden . . . people with so much. So I told her maybe two evenings a week so I could come here . . . that would be good. (2:2:4)

Then Salim said:

> To be honest, I found after a week, I've been coming here every day in the evening and . . . like I said, that's stretching my work by another two-three hours . . . I was really tired . . . by the time I got home, I'm tired . . . I don't want to overdo it too you know. . . . for the interests of everybody, for Nadia, for myself and for the people who are helping . . . I told them maybe after that, two nights a week would be adequate . . . you know, all the time you have to think of keeping the balance of so many things. So again I want to go home and rest and look after the children myself . . . to see to their needs. Because . . . I go there at seven o'clock . . . they are about to go to bed . . . so if I do this [visiting] every evening, I would be depriving the kids of me being around them for an hour or so before they go to bed. (Too much help, needs fluctuate) (2:2:5,6)

Too Much Help/Expectations of the Health Care System

The lesson to be learned is a hard one for volunteers and professionals who get involved in the caregiving to a dying patient and family. Helping/involvement is not an either/or situation. The "trade-off" is that non-involvement leaves the situation status quo and the status quo in the family experience of dying at home is less than ideal. The price the professional caregiver pays is that something has to be done with the obligations implied in hearing the story and seeing the participants. Putting the obligation away in the back of one's mind also does something negative to the professional (Kübler-Ross, 1975; Simpson, 1979).

Involvement/intervention also carries the risk that something negative will happen even if it is just criticism from peers. It is even more delicate if, as in Salim's case, too much help was given which became tiring to him. (One is reminded of Joe's fatigue at "too much advice.") It seems to me that part of the role of being a researcher or a practitioner is the need to make decisions and live with the consequences. The other obligation is to follow-up—to keep in touch with the family caregiver to see if the intervention went as expected. Easy lines of communication are essential so that the family caregiver feels free to say "To be honest, I find that . . .."

Salim quite frequently felt safe to tell the truth as he saw it about the experience of caregiver to a dying person. Salim's feelings toward the system, particularly the medical system, are instructive. He knew that he needed the system but during my visit with Salim after Nadia's death he was explicit in his evaluation of the health care system:

> . . . if you take doctors and the medical profession in general, what they have done in Nadia's case, on the average, it was good. The nursing service was excellent. The homemaking arrangement was excellent. So if you noticed, I have put excellent on nursing and excellent for homemaking but medical part is good, not excellent. And there's something maybe, I don't know if I have to repeat or not, I have some doubts of how things actually were developing with Nadia. The doubts I guess will be always there. I will never have an answer and I can't really do anything about it. But to me, the way actually I have seen it in the hospital—the medical system here is sort of systematic . . . some kind of schedule or process, sort of like at Chrysler; an assembly line. [There is] the big difference between a man working at Chrysler and a doctor but they somehow to me they have some similarity. In the sense that the doctor is not really involved that much and it's always—I've got this feeling here about the medical service in Canada. Although it is really good, but still they don't really give time to sort different case, case by case. They are sort of, even for cancer which is a most unresolved thing, they still go quite a bit with theoretical approach. Like with Nadia, they have gone through operation, hysterectomy, and then radiation and when the radiation failed because of occurrence in the level, they went and they had the chemotherapy. I don't know if that was actually the best approach in Nadia's case because what I have learned and what I have seen in this small instance of how the case has progressed . . . . (2:3:1)
>
> At the time I did not understand but by reading things, things were becoming clear to me. He had mentioned something about that removing the ovary or removing the growth or the tumor, it spilled out, and they did really as much as they could but it was not easy because of adhesion.
>
> The medical report after the operation. I read this and I didn't really give it too much thought at the time. Now after reading this and after reading so many things about cancer, I think now, maybe the course of radiation, it was not easy to glean as much as you can out of this kind of stuff. I think if they do it like this, although I am not the profession to judge it, I think more thought about giving her chemotherapy in the beginning could have

> been more logical to me.
>
> With hindsight is easy. Of course, the chemotherapy is harder treatment . . . (2:3:2)

Salim had, true to style, gone to the library for answers. He had been reading scientific journals as well as books for lay people. On his own, he tried to figure out what was happening. He didn't feel he could talk to the doctors as they kept changing: "too many residents and interns." As Salim said:

> So the cancer being so . . . very special . . . I think it's left a little bit too much for beginners. . . . everything looks very nice from the outside. I'm very impressed with the whole system . . . if you're having an appendix . . . but not with something like cancer. . . . Like to me there are things unanswered and, of course, that's fate and it's gone. Nadia's gone. Now it's—I don't know if things would have changed otherwise or not. Maybe not. I really don't know. So it's a little bit [pause] unclear to me and I will never—it's always there out of my mind. How effectively really, the whole thing.

Salim continues to reflect on the whole treatment process:

> It sounds so impressive money-wise and budget-wise but—and then, I was telling a friend of mine if I ever get struck with cancer, I will never get any treatment. Because looking at—really Nadia was okay until the time she started, physically in the sense that she was not really that sick, that she has to live six months only on IV and maybe the treatment have prolonged her life by three or four months or something, but her suffering for seven months. . . .
>
> Actually at the time she started the treatment, she was on her feet, she was in pain, but you know, she was on her feet and we were going visiting people and people coming and visiting us and all this. Maybe that thing would have lasted only two-three months, instead of a year. But maybe it was better off to have two-three months of reasonable life than a year of pointless, of pointless life. So, I don't

know. That's exactly how I feel, really, about the medical profession.

Actually I was going to the library and I was getting books and I was reading about the whole thing and, you know, differently now, I know when the whole things is—I know cancer is bad word. (Cancer is a bad word)

. . . you start putting things together and you start thinking, should it have been done really that way or maybe another way to do it.

R I'm getting a sense that it should somehow have been better for you both all the way along the line if you'd been given the information to work with and had some say in the decisions about what was being done. You needed more information?

Salim Definitely. Definitely. (Need for information) (Excerpts from 2:3:5,6,7)

Actually one of the things I would have loved to have seen was her chart. I had almost to sneak and try to look at it and see it . . . For example when Ellen was born. She lived a month in the neonatal unit. I was trying to go and look into her file. Maybe I'm nosey, more than I should be, I don't know, but it's my consent, she's my daughter and I want to know about—and a couple of times, the nurses, oh no, you're not supposed to do this and you're to ask the doctor. Or no—or something . . . oh no, it is difficult to understand. You'd better ask the doctor. And you know, actually, nothing I've seen was difficult to understand eh? Like either in chart form or figures, the numbers form and you can see in them actually how things were . . . (2:3:6)

Salim went on at length to ponder on the science of medicine and the value of all those tests that he doubted were "adequately analyzed." If ever I had seen a family caregiver in need of first hand information it was Salim, the engineer trying to make rational sense of his wife's dying. As he said, "Somehow, I've got the feeling that they don't really want to spend time with you. They just want to rush you . . . some of them assume somehow that you don't understand what they are talking about but I . . . think I can understand very well" (Need for information). Salim continued:

> After my wife had been classified as a terminal patient, I felt that the contact between myself and the medical staff and also between the medical staff and my wife has decreased tremendously. Actually a day or two may pass without any doctor going to see her. . . . The nursing therapist was giving my wife the medication on time. Everything is still as it used to be but not the communication between the medical staff and us. So I felt I had no . . . function after the medical staff know that it's a terminal case. They just lose interest for spending time with the patient and the family or they themselves feel uncomfortable with the situation. I really don't know. (Feeling isolated) (2:1:1)

Salim tells about reading about a doctor/patient relationship that to him sounds like the ideal.

> And the way he described his relation with ~~the~~ patient and how he sits with the patient and the family and makes some kind of contrast between himself and the patient . . . I don't know if such, to be honest, if such a doctor exists. Because the way he described himself is very—is beautiful if it's actually happening in, you know, in reality.
>
> That [pause] personal care, you know. (Need for contact with professionals) (2:2:23)

It struck me that perhaps Salin was reading too much. He was using the information and applying it directly to his own situation. Books and movies seemed to be his only source of information about the last stages of dying. Salim tried to pick up the cues:

> I just recalled this . . . they have actually moved her from doubled bedroom to single room and even that book mentioned that is an indication that the case is getting near the end, they move the patient to private room so they won't cause commotion in a multi-patient room. So they usually like the book was saying, you can hardly see death in the hospital because everything is done quietly and so that's why they try to provide single room for the person who is near the end. . . . it's so funny because when I read the book and something happen, I recall what I read. And I just try to associate—so, that's, you know, I don't know if that's an indication or what. . . . I've never seen anyone die, to be honest with you. I've never seen somebody die in front of me. Except in the movies. (2:2:29)

Thinking about the obligation inherent in hearing "the story" I wondered if the medical system would be quick to change. Would professional caregivers ever have enough time to listen to the family caregiver and provide the necessary information and "delicately balanced" help? (The need for information)

I did one of my interviews with Salim at the acute care hospital where Nadia was about to die.

I entered Nadia's semi-dark room. Nadia was half asleep. I went over to say 'hello' to Salim who was sitting well back, over by the window, reading. I went back to the bedside to see Nadia. They were using intravenous pain control as well as IV solutions to try to balance her fluctuating blood chemistry. I had brought some late blooming flowers and was glad to bustle about getting a vase, filling it with water and making room for it on her bed-side table. She was too weak to make conversation.

I wished that we could have talked. I had admired her directness. I recalled to myself the day she'd gone to the hospital. She had been lying on the couch in the living room 'watching' TV, waiting for Laurie to come. When we arrived, Laurie had a phone call to make and I went to sit with Nadia. She smiled and gestured toward the "soap opera" on TV. "Yesterday it was the city, good job everything . . . today it's The Young and the Restless." Then we'd helped her upstairs to pack her suitcase.

I asked her if it was okay to talk with Salim for a while? She nodded. Salim and I left the room.

Salim talked about how it was in there (in Nadia's room):

> She seems to be getting closed in now. Before she—it's very obvious to me that she is really not caring for the outside world.
>
> [Sigh] You know I was tired. I hate to use the word, but maybe I will use it. I was sometimes bored . . . more restless like . . . not doing anything which sounds very bad . . . by six-thirty I just want to leave because . . . I'm not doing anything—tired—bored . . . hungry. I want to come [home] and have a bite to eat and rest . . . [The staff] would say, okay, stay, up 'til eight . . . You pace the room a few times, you go out . . . so although I know that I could stay a bit longer but I wasn't even staying that long . . .

Salim continues:

> You can see she's in bad shape. The calcium is—actually it came down a bit and then it came high again. Today. And so that's the big reason why she's quite drowsy now. Which is an indication again of the tumour maybe running wild or uncontrollable so I, you know—although I don't really think of—

> you know, I just live day to day . . . and you can see what's coming down the road . . . (2:2:1)
>
> Because it's—that's what's really bad about this kind of—any terminal illness, you know. You just give up—and really hope, there's not really much hope of the situation but just trying to—like sometime when I talk to cheer her up, I know that I'm lying to her and I'm lying to myself—I'm not, you know. It's not really—it's strange thing. I don't know how I am doing it but to think about maybe before or after the fact or after the experience itself, it sounds sometimes, you know, crazy about how you went through that.
>
> Because it's really something—you used to see in the movies all your life, to know somebody very close to you and you know, you know, she is dying and how can you come and talk and say the things. Try to pretend it is normal, like—
>
> It's really is strange like how I am doing it. (2:2:12)

Salim thought that he would not be able to manage "this" at home. His main concern was for "Nadia's health." He did not want her to be deprived of anything "that cannot be obtained at home." In her condition, "I would not even think of taking her home. If even that option were available to me. . . . the medication may not be easily obtained at home" (2:2:7).

Salim said that having Nadia home for the last month had been good "even with her health being weak and all that, I would say home is good . . . good for everybody" (2:2:7).

Salim told me that two things were bothering him. Nadia had told him that she was too tired to see the children and the other thing was that she didn't even want to talk to her family by phone. She used to get so excited at the idea of calling her father. They are very close. "Maybe I'll get a phone put in there."

She's really "drawn into her ~~self.~~ When I used to get here five minutes later than the usual time she'd wonder where I'd been—now . . . she's not reached indifference about me yet. She may. She may come to this point. But I think maybe that would be just—the end" (2:2:9).

He was talking to himself now:

> Although when I did bring the kids [even when she told me not to] . . . they were all over her and she looked quite, even, you know, out of her inner self. She was smiling and all that. [Pause] Yeah. Yeah. Actually another thing about her maybe I should bring the phone and just make the phone call [to her father] because . . . with the children I did that . . . you know, on my own. (2:2:10)

Salim lately had become used to thinking to himself and making unilateral decisions for both himself and Nadia.

He told me again that he could never do at home what they were doing in hospital. Salim said:

> I asked the nurse to give me a list of what she is taking. I tick them off. I get to recognize the names and the function. I see how they change. But they are assessed every day by the experts. I feel helpless with Nadia . . . I can only spend time with her . . . so at least I'm trying to be involved, you know, as much as ~~I can~~ by knowing what's happening. (2:2:13,14)

We had talked for quite some time. I said that perhaps I should go? Salim said, "At least for my part, I don't have a sense of time." I came home and memo-ed (September 18, 1984): "Dying is not dignified." "Death may or may not be [dignified]. [Dying] comes down to bowels, bladders, sweats, emaciation, dry mouth, pain. Hospital/clerical [is] set up to routinize the above—equipment, scheduling, staffing."

Three days later Nadia had died. One week later I went to visit Salim at his invitation.

The visit is reported in Salim's own words as it happened. I said some encouraging things—too many, I think, as I read through the transcript. But mostly I let him tell me about whatever came to mind.

Salim Sometimes I wonder, honestly [how I coped] because [pause] it's not easy. It's not easy. And it's not going to be easier for a number of years and how I, how I don't know, how did I go through all this without really breaking? I maybe cried at the occasion, you know, especially at Nadia's death and all that and the first day or two. But [pause] things are . . . I've been reading, even reading, you know, maybe this habit of reading I shouldn't really have started because it puts me in doubt about talking about this bereavement period—it is good relief and all that. And if you don't really have natural outlets that may affect you physically or otherwise. I wonder but I don't think I have actually expressed myself in—I don't feel that, you know, I'm going really to bereavement as such. I'm not, I'm not [pause] I'm not sitting crying every day . . . I'm not really. You know, I have done it only as the day of death and the following day at the burial. After that, I haven't done it.

Okay. So, sometimes I wonder. Have I? Is this natural? I sometimes—I wonder why—everything I read, you know, they stress that okay you should really . . . at the time of bereavement go and cry, shout, swear, do something. I haven't done any of that. (2:3:9,10)

R [does a counselling response] How do you feel inside yourself Salim?

Salim Sometime anger. Sometime anger. Anger about so many things.

R Um hum.

Salim But at the same time, with those children around, I can't really—like I'm talking to you—but in front of them, I can't allow myself to be sad because they won't even understand what's that. So I have to play with them, take them to the park, for a drive and this and that because I, you know, I have to give them a little bit of civility and that's how they—that's a way I can do it. Because there's no point of blocking my door and be sad and they don't know what's happening. Especially when they're—you know, if they were older, a bit older, you know, you couldn't even—and that's what they say, you know, little children share in the bereavement. How can I, how can I make them share? It's for them it's impossible. Maybe they are talking about older kids but different, not one year and two and a half. Like, you know, and this, you know, even in those books—they all, children have to know and have to participate and all this but, you know, how those children can—how can Ellen participate in anything? You know, it's rather impossible, huh.

Maybe this is some kind of outlet. [Pause] But mainly the anger about really how things are—For some reason, I feel it is just a life wasted. Nadia's life just wasted. She did not fulfil her, you know—her, her being. And it's very unfair. [Pause] [Sigh] I think it's time for more tea. Do you want me to warm it a bit?

R No, you know me, I have it—this is a good temperature. Thanks. (2:3:10,11)

We both take a break from the intensity that was building and talk about other things.

Later Salim got back to talking about the need to put on a good front:

Salim Then I have to put a different face, either in front of Nadia before or in front of the kids before and after. Because definitely how I feel was not what was reflected towards everybody. Say now, okay, take an example of now with the kids, I play with them and I, deep inside you know, I don't feel really, you know—[like being joyful].

But I have to pretend a lot and do all this with the kids and so it is maybe something harder, I don't know, what other means I can handle the situation.

R Do you feel as though you have to kind of hold yourself together for—to keep some sort of order for the family?

Salim Yeah. Yeah. Because otherwise those children would be completely confused.

R Um hum.

Salim So [pause] And I don't know if, you know, like according to the latest in [pause]

R The books?

Salim Psychology and stuff like that, you know, I've tried to understand child psychology and all this kind of stuff. Is this the best way or not, I really don't know. But, you know, just the best I know how, you know, that's what I'm doing. (Excerpts from 2:3:12,13)

I thought about books and theory and the unreasonable amount of power the professional holds. It occurred to me that we ought to keep a proper sense of proportion about the amount we really know about "basic social processes." We can only conjecture and let everybody know that theory is only conjecture—useful perhaps, but tentative.

Salim seemed to want to talk about Nadia some more. Salim starts with his surprise at the way Nadia died. The following excerpts are from 2:3:15-19.

Salim Actually up to the last day—actually her death was a surprise for me, surprise in the sense of the timing, not of the death itself. Because I was under the impression that she was going to go into a coma and it would be a few days. But up to the last, up to the last—actually, it was so strange . . . because at lunch hour I got visitors coming from work to see me and I didn't want them to see Nadia. She was in pain more often. So I went down with them into the lounge and we were talking. It took one hour. You know, she died in that time. So I left her and I got back, you know, and she was dead. So it was a big surprise because I really wished that I would be with her at the time but—if Somebody's planning things upstairs, you know, I think that's the way He planned it.

I wanted to be [there]—I slept in the hospital the night before. Because I knew things are not going well now at that time and things were progressing maybe worse. But I was not expecting that it would be that fast. Like I thought it may take a week or two. But not that sudden.

R Um hum. It must have—

Salim Because you saw her on Monday. Actually, she was almost the same, maybe slightly in more pain, more frequent pain, than the way you saw it, up to the last minute. Actually, one thing that I wanted to phone her father.

R Yes?

Salim And I got the phone in the room. I dialed for him—his phone was out of order. But then I phoned here and I told Colleen. I thought her father may phone because he was phoning once a week or so. I told Colleen if any phone call came from Tunisia, tell them to phone me at the hospital.

R Um hum.

Salim And sure enough, on the day she died, he phoned here. He got the message. He phone us there. It was around eleven o'clock. She died at one o'clock. And he talked to her. And that's a coincidence in a way, like—I'm glad that I got this phone in this last couple of days. So he talked to her and she was in pain at the time. She couldn't talk but definitely she heard him and he heard her. (The patient lets go)

I thought things would take much longer than that but . . . I went for an hour with those people. I wish they didn't come, to be honest with you. But, you know, I have no slight idea that that may happen. You know, that fast.

R No warning.

Salim Yeah. [Pause]

Actually thinking back, maybe . . . I wonder maybe I should have done a bit more because I was just sitting reading, not doing much, eh. I don't know. [Pause] Like I would have been [pause]. Time-wise even . . . you know, except that last week or so when I was able to be there, you know, a few hours in the evening which definitely helped but thinking maybe I—but again, it's difficult definitely really to say—Even with that week, you know, I could have stayed longer every day but I was, you know, I don't know, like after hour or hour and a half I don't see myself doing anything, you know, like sitting there. She dozed off, on or off. We were not really talking much except she wants something, you know, she wants water, she wants this and that. I go and get her what she wants.

R Yes.

Salim Something done so I can, you know, I'll go. I was, you know, helping her to the commode and, all the time because she was not able to stand up on her own. . . . in the last days, the doctor wanted to have the—what do you call it—the drain so she doesn't have to stand up.

R Catheter?

Salim Catheter, yeah. She was aware of that. She said, no, no, I don't want it. And I told the nurse, okay, if this was the case, we might as well, you know, not to. And then I sought the resident doctor out and I told her, you know, no, she doesn't want it. She says okay, or for the time being, let it go. Let it be and if, you know—that's why I thought . . . she said, okay, maybe later, you know, we can still do it when she's not—You know . . . the day of her death . . . like I had no really—

R You had no warning or no sign.

Salim Yeah. And see, even Monday, when you came here, she could have died at the time, the hour I was talking to you. Could be because the occasion on Thursday was not really much worse.

R Yes.

Salim Then the occasion on Monday. And then I was— I have no [idea] . . . that that can happen. So I—[it] must have been very, very short or it was there and I just did not sense it or something. Because you know equally appropriate time could have been any day in the last week.

R Yes.

Salim Because nothing was terribly changed in her condition. Although her calcium was high and the potassium is quite high. [Pause] And that was what must have actually happened. She must have lost—she died of a heart attack I think. She must have.

R Because in a way, although it had been a long time, it was very sudden at the end?

Salim Yeah. So maybe, her system could just not take the high calcium and the blood and that caused heart attack. That's the only explanation because it cannot be the cancer. Cancer, you never die of cancer as such, you die of complication of it, you know. (Trying to make sense of Nadia's death)

Salim continued to muse about possibilities. He seemed to be remorseful at not being with Nadia at her death and at not having done enough for her during her last few days of life. (Remorse at not being there)

I remembered that Salim liked information to help him deal with past crises in his life. We talked about the possibility of Salim's reading Nadia's medical chart.

Salim	Actually I would love to see that [the chart]—the whole, if I could see the whole thing, just to read it.
R	Umm. [Pause] It would fill in some pieces for you.
Salim	Yeah. Possibly. Yeah. Or answer some of the questions. Actually, Dr. ________ met me after. Both he and the resident, they came and saw me and they said okay, if you, after some time, if you want to come and ask any questions, you know, feel free to come.
R	Good.
Salim	But again, you know, I don't know if I can actually have an access to go for one hour and look into her file, you know, without, you know, without asking even questions. I—
R	You'd prefer to see the material written in front of you?
Salim	Yeah. Yeah. It's sometimes that's more—
R	Reassuring?
Salim	Reassuring or more filling—
R	You can take your time with it.
Salim	Yeah. Browse into it and, you know, if that can be done actually, that's the best thing.
R	Umm.
Salim	Just go and go through it.

We decided that we would try to get Salim access to Nadia's medical record. Salim continued to talk about the day Nadia died.

Salim Actually, the day of her death the resident doctor was talking to me. He came up and he wanted to see me and then we went out and we talked and he was telling me that the situation was really bad and they're going to withhold all medication. It's pointless now.

And then he was saying, okay, you know, she may go into a coma or something. I was expecting that that was going to happen. Then once—no, no sorry, that was Wednesday. (Losing track of time)

The day before her death. And then that's when I decided I'm going to stay in the hospital.

R That night.

Salim Until it happened. And then I phoned work and told them I'm not coming until, you know—things are bad here and I'm not going—I'll be in touch with you anyway. So—they said, okay, maybe you should go until her death. I said, what's the point? You know, I don't think maybe it's a good idea to go and tell people that you are going to withhold all treatment. He was saying okay, we are doing everything for you and not to feel in pain, stuff like that, but not . . . You know. To me it was clear, you know, this condition is really bad.

But—so, no, I, like I do not feel that I want really to tell her that she is dying. I don't know why. Why it was. Like according again to the books, know, the patient should know and—

R But it never seemed—

Salim But it didn't seem to me that it is [pause] would have better so. At least we can remove that barrier between us maybe a little better. I don't know.

R Um hum. Again it's hind-sight isn't it?

Salim Yeah. [Pause] Because maybe both were avoiding to face, to face the fact but [pause] Difficult to say. [Pause]

Like actually I almost think I was afraid, you know, it was a fear that she may have been going through . . . pain. Painful period. I think that that would have been very hard to me to handle.

Because I could not really, you know, it was hard for me as is, you know. Although it was not out of control, like all the stories about people going—you know, cancer patients, how painful their last days and how it's unbearable and they all talk about they should give them heroin because, you know, what's the point of this and that, even if . . . but—maybe for the heroin, you know [pause] bitter end, that she didn't really go through. I don't think she went through quite a bit of painful period. . . . last two days and . . . last days were not—

R Anything like—

Salim Well not—anything like I thought it may have been. Like not like sitting in bed unable to control the pain or, you know, in agony. She was in the last two days maybe not quite as before but still—

R Nothing like what—

Salim Nothing [like] the thing I was imagining. What if that happened, you know, and continued for months and months? Because I asked the doctors on every occasion, what would be the . . . pain-wise, you know? How that could be? . . . What they told me was I guess correct ~~that it~~ was not really very painful this kind of cancer. And I think it wasn't. So that was maybe my most fear. [That] would have been very hard.

R Um hum. To have had to watch.

Salim To watch and see her in—

R In pain.

Salim In pain for any length of time. (Pain is greatest fear) (2:3:38-40)

Salim had a great deal of difficulty putting Nadia's death into perspective. He talked at great length about his regret at not having been with her when she died and his need to know how she had died. "Nobody dies of cancer. It must have been a heart attack."

I have left some of the circular language in the body of this chapter to give something of the tone and feeling of Salim's attempt to make sense of Nadia's death. Several extra pages from the transcript are given as Appendix 7 to provide more information concerning the painful contortions that a caregiver goes through when frustrated by death (2:3:27-32).

Salim confessed to feeling bored, just sitting and waiting and watching Nadia. He said that they had never talked about death or dying and that maybe he needed "the talk" more than Nadia. He also talked about "after death" and wondered out loud what could be happening to the person at the time of death. Salim surprised himself that he wasn't "too scared" to come back into the room and to touch Nadia's body after she had died. Salim's account of his feelings reminds me of Croushore's article mentioned in Chapter 2—It's hard to sit with death.

Salim talked further about the care that he was able to give to Nadia when she was home.

> Salim There was no pain involved whatsoever. And I knew it was, actually, you know, the thing that kept her alive more than anything else you know [was the TPN]. I just had to press the caps into the bottles. Which I gave her for months.

R So you didn't have to 'psych' yourself up to do any of the physical care? It was more—

Salim Machine-type of hookups and procedures are just numbers to her and I know it was helpful for her.

With the time she was throwing up or something like that—no I didn't mind it really. Helping her to, to, you know, with the washroom and stuff like that quite often. No it did not bother me, you know, it didn't bother me in the least.

R Just felt like you were—

Salim At least of some help. Because otherwise, I was, you know, not helpful in any other way. (It helps the caregiver to do hands-on care)

But I can see maybe in the last couple of days, or the last three or four days, it would have been—it would have been difficult. Because the assessing hour to hour her pain and giving her—because they were giving her, you know, the pain killer by injections which I was—I would not be able to do that here, you know. To inject any kind of painkiller was completely taboo I guess for outside of hospital. The only thing that she was, she had that they allowed as tablets, but not as injection. And the tablets would not have helped as much and in the last couple of days they were giving with injection, you know. (Not able to give injections: taboo)

With the children around . . . too. But [pause] that's you know, the only thing, for her own sake of controlling pain but like if she would have not been in pain I would have preferred it if she is home. I wouldn't have minded if she had died at home. (If pain controlled home death preferable)

Actually I thought it would be scary like, but you know, even in the hospital after that happened and I . . . I went back to her room and sat with her for a while [pause] and the nurse was there, to be honest, you know, so, the nurse who was very understanding. She said, okay, you know—I was a little bit maybe, a little afraid but, you know, I don't know. She said okay now if you want to hold her hands and I did touch there you know. You know, the first time I've seen a body, you know.

R A little apprehensive at first.

Salim Yeah. You know, I—what do you—[pause] but [pause] So, I don't know, it may have been scary here too you know, especially if it happened in the middle of the night. I don't know, you know. Hard to assess. But at least at the hospital you know the nurses are around . . . and even with this I was a little bit apprehensive, you're right. In the beginning. But after that it's okay. To be with her, you know, after the fact. [Pause] At least [if] we were home, I would more likely have been with her at the last minute, you know, more likely. [Pause] So. That home part was not actually—like again they say always it's hard—I didn't find it as hard. Actually I sort of—I didn't mind it all. Even that she was not in the best condition. I think we, we—between herself and I and the homemaker, Colleen, we handled that actually ver well.

We even had Ellen's birthday party here. It was a month before—a month and two days and she was, you know, she was okay and it was a very nice day.

R Um hum. [Pause] I think Colleen was saying she brought her kids and—

Salim Yeah. Yeah.

R She had—

Salim She had the kids here and a friend came over and we had very nice—we sat out, it was August, so we say out in the back yard and we took pictures of everybody and those were the last pictures taken of her anyway. [Pause]

R Glad you have them.

Salim Yea. [Pause] [End of tape]

The visit had stretched on for 2 1/2 hours. It did seem time to leave Salim. I had a sense of 'closure' even though we were going to be in contact concerning Nadia's chart. When I came home I wrote a memo.

October 10, 1984

> There were some additional thoughts that Salim expressed before we started the tape and one was about the children. Joel is still going through the clothes in the closet and saying "this is Mommy's and this is Daddy's." Salim had not yet done anything with any of Nadia's clothing or other possessions. The other thing he expressed right away when I came in was the problem of faith. He's planning a trip to Tunisia either at Christmas or in March taking the children and going for five weeks. But he said there there's no openness to be angry at God. There's no way you can express any kind of doubt. He felt freer to do that here. It's very closed community back in Tunisia.
>
> The other thing that Salim expressed before I left was I asked him about the way we were doing this [research] and he said he would never have answered a questionnaire and would have felt put off if I'd started to ask him questions on the first visit. That he felt comfortable with the way the process was going and very interested in the results.

Support Matrix of the Family Caregiver

Salim, although far removed from his family roots may not be a 'unique case.' Salim had been divorced and remarried with two small children. People are now constantly on the move and divorce is common. There are many potential family caregivers who will not have a very well developed support matrix. Salim was ambivalent about family support.

Salim So the problem actually—my case maybe is very unique. You know, in the sense that I have no support . . . family support, eh? Even the people who came from Tunisia they came for, you know—

R Short period of time.

Salim Short period. And not really to help me as much as to see Nadia and comfort her and so they were actually, to be very specific, they were a burden on me.

R Yes?

Salim You know, I did not mind at all, you know, that's beside the point. But it was not really a help to me. (Salim is ambivalent)

R But still it was more to do.

Salim Yeah. Because they are strangers in the country. They can't even—I had to explain to them how to take the bus even . . . and make sure they got there and I was looking after them actually more than they were looking after us.

R Yes.

Salim So ours is a case . . . . most cases like I see around, like I see around in the hospital most patients they have their family and even they take turns to be with the patient and so our situation actually is very hard if I have to think—because it's unique in the sense that they don't hardly—[pause]

R It's only you. (2:1:11)

Jennie

Introduction

Jennie's family is different from Salim's. Jennie had taken on the care of her eighty-three year old mother-in-law who was dying of cancer. Jennie was the third "primary family caregiver" I saw during my field work. Jennie was forty-five at the time of the inquiry, had raised her family and was ready to start on her own career. Her mother-in-law's needs superseded her own. Jennie said to me during my second visit:

> It was just a few months ago I was sitting out there [on an acreage], one husband and one daughter at home and now I've got a grandchild, an older daughter at home, my younger daughter, my mother-in-law's got cancer and my father-in-law comes in. It's the revolving household. [Laughter] I sent my daughter out to buy more sheets for a bed downstairs to accommodate my husband's Cousin S_______'s coming out to give a hand. (3:2:1)

Jennie and her husband George had moved into the city into his mother's large multi-storied home in order to take care of his mother, Mrs. J. Not only had Mrs. J's cancer been deemed untreatable and her death was "only a matter of time" but Jennie's single daughter had come home with a new baby. There were several generations under one roof and those generations spanned "6 months to 84 years." This was an extended family with more "help" coming; a veritable throw-back to the 1930's. Salim would have considered them to be very lucky.

Comparison to Other Informants

Jennie's story is particularly instructive. Here was a large family, the kind that Balfour Mount wrote about with nostalgia (cited in Chapter 2). I would find whether an extended family like Jennie's would have a "better time of it" than did Salim, for example. I thought that Mrs. J's short "trajectory" could perhaps make it easier for Jennie than, for example, Joe's stressful experience of following Nan's convoluted process of losing then gaining time.

Jennie's support matrix included: George, her husband who is Mrs. J's only son; Theresa, the homemaker; three daughters, Donna, Louise and Debbie; a six month old granddaughter; a son-in-law and Mrs. J's estranged eighty-four year old husband who sometimes visits. Sara, George's cousin, was soon to arrive to help out. Laurie was the J's home care nurse. Quite a group! Jennie called it her "revolving household."

Jennie's story, for the most part, is written in her own words. Her own words tell the story best. I will use categories that were identified from the data as headings and allow themes to surface from the thoughts and feelings as Jennie and her family and homemaker express them.

The visits after the death of Mrs. J are reflective and demonstrate the difference between field work as the caregiving is happening and the reflections that take place after the death of the family member. There are qualitative differences between the more analytical categories/headings and the underlying essences of the caregiving experience that surface in the themes. The differences are further explored in Chapter 5.

Jennie's Story

When I first visited Jennie she was too busy to spend much time analyzing her experience. She was fully occupied with the daily—and nightly care of Mrs. J. She took time though to talk to me about some of her feelings about her new role of 'primary family caregiver' to a dying person. The first item that came to Jennie's mind was resolving her fear of death. Jennie said:

> I had never had experience with anyone that's been terribly ill or terminally ill other than that my father passed away last year, September 10th, and that's the closest person to me that has died. I found it quite a traumatic experience really. I had never seen a dead person in my whole life and I always went ah! I never want to—that would be terrible, you know. I'd look the other way rather than look at someone who was dead. But after my dad had passed away—he'd been—he'd had a massive heart attack and he was very, very ill for three days and in intensive care—
>
> And when they came out to say that he had died, I said I want to see him. And I was the oldest of all the children so we went in to see him and he looked so calm and peaceful, I thought I never wish him back. [Nervous laughter] You know. And it kind of resolved a lot of things in my mind that he was perfectly fine and he was in God's hands and you know—and—But you know it's funny, you know, my mother never did see him. She had gone on holidays and he died while she was gone and she wouldn't go and see him. (Fear of death is common)
>
> [Reflecting on the present] But I think it's a peaceful time for us, in a way. I feel comfortable with her [Mrs. J]. I never thought I would. We've had people here, especially relatives that know that she's dying, and they find it very difficult to go and talk to her. Like what do you say to someone who's going to die? But I haven't found that and don't ask me why. Maybe it's because she's accepted it. That I don't have to worry about that. (Patient's

> acceptance of death helps the caregiver resolve fears) (3:1:1,2)

Jennie relates her past experience with her own father's death with her present experience of caregiving for her dying mother-in-law. Jennie continues:

> I think that the health care nurse Laurie has been very straightforward and frank and—I think too, you know, like grandma has a belief that she's in God's hands and what will be, will be. She talks about when she gets her wings. [Laughter] (Frank attitude of nurse helps caregiver) (The use of metaphor to describe death) (3:1:2)

Jennie continues her reflections about what this caregiving experience is doing for her family:

> I think it's a good experience for our family too because you give and give to your children and all of a sudden they have an opportunity to give back to you and they have. You know, Donna [Jennie's eldest daughter] will say, you look tired, I'll come tonight and you and dad can go out for supper and I think—well Donna's the oldest—she's twenty-three and I think you start to change around that age from being a care-free child to thinking of the rest of your life. Sometimes when you're eighteen or nineteen, you think boy, when you're twenty-five you've had it, you know, life's over. [Laughter] (3:1:2)

Jennie's other daughters are helpful too:

> . . . they know that she [Mrs. J] will be gone. And not only that but she did look after them. She was a second mother [to Jennie's daughters] at times when I was ill. (Caregiving is reciprocity) (3:1:2)
>
> But like Donna said to me one day, she said there's a lot of times that they fought and had words but she said, "I'll really miss her." (3:1:3)

Jennie and Theresa, Jennie's homemaker who had joined us, began to talk about Mrs. J and some of her comments about dying. I began to see that this preoccupation with 'what the patient says' and 'what the patient does' is an essential part of the caregiving experience.

Jennie She [Mrs. J] really enjoys the baby. She did remark one day that "I won't know this child and this child won't know me, but then that's life I guess."

Theresa She had said another thing the other day that was sort of interesting. I was sitting on the chair with the baby and she was just sort of looking up and she said, "Isn't that funny?" "There's a little life that's beginning and here's one that's ending."

Jennie Yeah.

Theresa She said, "Interesting isn't it?" [Laughter] (Regret: Acceptance)

Jennie Yeah. Just a comment or an observation.

Theresa And then she said, "What do you think it's all about?"

Jennie When she first realized that she wasn't going to be living much longer, she did take quite an interest in reading the prayer book of the Anglican Church

And she did a lot of reading for a long time and whatever questions in her mind must have been resolved because then all of a sudden she kind of gave that up and started reading to pass the time. So— (Resolution) (3:1:3)

Later:

Jennie She makes the remark at the odd time that it's too bad that she just couldn't take an opium pill and drift off.

R She was saying today, "I wonder how much longer this is going on?"

Jennie Exactly.

Theresa Actually she has said a lot. She'll say, "Do you know how much longer it's going to be?" She was asking Laurie the other day if she had any idea.

Jennie Well, I mean if you can say you accept something—still it's an unknown and anybody is afraid of the unknown and—

R Yes. . . . Saying that she's at peace, accepting, doesn't necessarily mean that's once and for all.

Jennie Oh no. Her mind works all the time.

R Yes.

Jennie Her mind never quits! [Laughter] (Talk about patient seems necessary) (3:1:4)

The patient appears to be central to the caregiver's life especially when the patient is at home and becoming totally dependent on the primary family caregiver. Perhaps it is appropriate then, that I describe Mrs. J at some length because her presence and then lack of presence is a preoccupation of Jennie's before and after Mrs. J's death.

Mrs. J

Mrs. J had been an accomplished concert pianist, had travelled widely and had in fact met her husband aboard ship during one of her concert tours. She married rather late in life and her only son George was born when Mrs. J was forty. Mrs. J wanted George to be as cultured as she and she tried to interest him in classical piano.

George turned out to be a farmer/construction worker who played country/western guitar in his leisure time. Jennie describes the differences and similarities between Mrs. J and George:

> . . . she was a concert pianist and she always wanted him to play the piano. And he was good but because it was her will that he play the piano he rebelled and it was really a thorn because music was her whole life and he became a real macho type. Although basically, down deep, he always, you always have those qualities no matter, even though you get off the line there. I think deep down you always have the qualities. (3:1:4)

Jennie talked at length about the difficulties of Mrs. J's and George's relationship. For years there was in fact nothing but anger between them. George became an alcoholic. Mr. J Sr. moved out. Mrs. J kept to herself. She was unhappy but too proud to make the first move toward reconciliation. Mrs. J lived alone for several years in this large house, with her limoges china and sterling silver and Brandy, her dog. However, surgery for cancer that was likely untreatable broke her resolve. She called George. Jennie describes the situation:

Emotional and Other Benefits of Caregiving

> And he's [George] become quite close to his mother and maybe, maybe this is the way it was meant to be because they hardly were ever in the house five minutes that they weren't 'yurumum' [fighting]. [Laughter] But when he first found out that his mother was going to pass away, whew—I was in Westlock. I had Debbie in the dentist's chair with her mouth frozen. He got on the phone and he couldn't talk. He was crying. I said, "What's wrong?" And then he said, "It's mom. Meet me in ________ Hospital." So I grabbed Debbie out of the dentist's chair [laughter]—the dentist came back, has no patient—roared into town and she had her surgery—we were in about an hour before her surgery and we spent an hour with her. But we didn't think she would make it. She was eighty-three at the time and she had—it was an obstruction—So it had to be done and he just had an awful time. So maybe having

this time with her has let him resolve a lot of things. (Cancer: Changing family relationships) (3:1:9)

George often took "the night shift." Jennie describes the care:

Jennie	[George] goes in in the middle of the night—he'll lift her out of bed and, you know, her—what can I say. She doesn't have hardly any clothes on and—but he cares for her. He cleans her up, if she happens to wet in the night. He'll take her slip off. He'll clean her up. He'll put a new one on. It's not an embarrassment to him. It's not—I don't think he even thinks of it. He just things that this is what he's going to do to make her more comfortable. (3:1:9) [Pause] You know, I keep thinking back to the fact that he looked after his mother so well and maybe men—a lot of men aren't capable of that. For instance, we had one relative come that hardly would go into grandma's room, you know, he just wanted to be away. And he was in his mid forties. He wasn't really a young chicken but—I have to give my husband a lot of credit for the way he was with his mother. And for the fact that they fought [laughs], you know, that they weren't—they were close in their way—but because they were so—both dominant. She was the dominant one in her and her husband's relationship and my husband's the dominant one in ours. You know, I just still keep going back to the fact that [this time together] was good for both of them. It was just great. (Seeing the other's strengths) (3:4:19) Yeah. Her boy, she calls him that, her boy.
R	Does she?
Jennie	Yeah. See his baby picture up on the dresser there?
R	I hadn't.

Jennie	Yeah. It's a little picture of him when he was a little boy. Actually not a baby picture, but when he was a little boy. So—
R	They've really come close to each other then?
Jennie	Yeah. (The positive effect of 'doing for' the patient) (3:2:3)

Mrs. J had always been something of a character. I'm not sure why I expected her personality to change drastically 'just' because she was dying. My most 'typical' memory of her was: Mrs. J dressed in her best gown ("no point in saving them"), curled up in bed, pillows propped comfortably, Anglican prayer book put aside, reading the most lurid novels—French Revolution, Forever Amber, etc. Jennie had trouble keeping her supplied. Mrs. J often read through most of the night, then slept in the daytime when there was a comfortable hum of activity in the house. Mrs. J's choice of reading appeared to me to be out of character but Jennie remembered Mrs. J's scolding about, then trashing, novels that the hired man brought home only to find these undesirable novels would reappear in Mrs. J's kitchen drawer.

After Mrs. J died, I returned for two visits. We reminisced about Mrs. J and more of her personality was described:

Jennie	She enjoyed reading. She read everything and anything that she could lay her hands on—you know, she always was an avid reader and that certainly helped her pass the time.
R	Um hum.

Jennie And I think, too, it helped her get out of her bed of pain or bed of boredom or whatever it is that—

R She could be transported away on the adventures.

Jennie Exactly.

R And the wilder the adventures, the better, she was saying.

Jennie That's true. [Laughter] That's what she said about the last book, she said, well, there wasn't much sex. [Laughter] Holy cow!

R Disappointment!

Jennie Funny. She was a funny person.

I'll never forget when we were farming. We had some young hired help in those days and one of them brought in that book called Mandingo. It was—the day when that was—like Lady Chatterley's Lover—they were to be burnt and everything else. Anyway, she confiscated this book and quietly read it herself and said it was just an awful book and [laughter] tut, tut. But you know, she had to do the research first so—

R To protect the rest of the family.

Jennie Exactly. So that book after she read it went in the burning barrel. [Laughter] Funny person. We were talking about it the next day. You know, we said well the tyrant is dead. And I know this is a funny statement to make.

R Um hum.

Jennie Because she wasn't—of course she couldn't be the tyrant when she was ill but [pause] she was the boss in the household.

Mrs. J, although dying, did run the household. When I visited, I definitely went to see Mrs. J first. She would give me a "hard time" about something. Being Irish, for example: "I suppose you're Roman [Catholic]?"

As usual when I visited, we talked about Mrs. J's latest skirmishes:

Jennie And I think a younger person always has the idea that an old person's mind doesn't work well any more. And they're not quick any more. But I found that not to be true. I know several people in their eighties that their minds are just as quick.

And she doesn't forget a thing. In fact, she was getting one of my daughters some money one day to get something and she put out this money and she said to Louise, "There's a one dollar bill." Louise said, "Grandma, that's ten dollars." She says, "Just checking." [Laughter] She wasn't getting cheated!

R You don't put one by [her].

Jennie Being on codeine, she does get a little forgetful. Like she'll say ten minutes after, "have I taken my pill?" But on a long-term basis, she remembers everything. (The dying person is central to the care-giver's life)

Later Jennie talks about another of Mrs. J's activities:

Jennie Donna [Jennie's oldest daughter] had said to me many, many times, you know, she said I will miss her. [Laughs] And it's true what my husband said. If she would have been a placid, milk and toast type she might not have left such a mark on her life but because she was such a domineering, run everything, like, even for instance, August 14th, was Louise's [Jennie's middle daughter] twenty-first birthday, so we had a birthday party and we rolled her from the bedroom into the dining room on her commode [laughs] and she had a few remarks to say about that. That she sat at the birthday table on a commode—and had just a little birthday party. But just before that she had sat up in the bed and gave all the instructions to everybody—polish the silver and what tablecloth to use and she had us all going. You know, everything had to be done just right.

R She was still the hostess.

Jennie Oh yeah. [Laughs] And Debbie and her friend—I said you'll have to polish all that silver. [Laughter] And they're saying, mom, do we really have to do all this. [Laughs] And she never, you know, she made sure that the table was set properly when we got to the table. But mind you, she was so sick at that time, that she didn't eat anything. She might have had a spoon—but really nothing. (3:4:8)

Although there were good memories like the birthday party, there were also the more difficult times. Jennie talked at length about her need to "learn by doing" physical care for Mrs. J. Jennie talked about Mrs. J's pain and the need to control it.

About Pain Control: The Need for Information

Jennie When she feels good, when she's pain free and she's reading her books and she's comfortable, I don't think she really thinks about it too much. When she's uncomfortable she says, she said, oh God, Jennie, how long is this going to go on? And I've heard her ask Laurie that too. (3:2:16)

During my first interview with Jennie, she had talked at some length about pain control:

Jennie I think the worst thing that she worried about was pain. But then I think all this—the minute you say cancer, that's the first thing that comes into your mind, the horror stories that a person has heard and I know my grandmother kept her father at home until his cancer was so advanced that they did put

> him in hospital—she gave him injections and like my aunt said, he used to beg her for injections and she'd say, "Oh I can't"—it's every four hours or whatever time span, and it was really really hard on her to watch him and I think she would probably be tempted to do it anyway. You know.
>
> But I think they've made some steps forward in that regard now. And Dr. R______'s assured her that she would not be allowed to suffer. (3:1:10)

Jennie continues:

> Well she said to me, "I don't want to go out screaming. I don't mind going, but I don't want to go out screaming."
>
> And she asked many, many times the health nurse, the doctor—she had to be reassured many, many times and my husband worries about it too. He doesn't like to see her uncomfortable and you know, you can't blame him. (The need for pain control)
>
> She should have a pill once every four hours and like today, it was six hours. Well it was too long and I ended up having to give her two pills because she got too uncomfortable and that was my fault. I think because I got overtired . . . (3:1:11)

The Primary Family Caregiver's Method of Pain Control

Jennie	Sara will be here at night time and she can—I know that she will get up in the night if grandma rings. That's another thing with this morphine base too. Like sometimes she'll ring three or four times right in succession, especially in the night time, to ask me funny questions.
R	Umm.
Jennie	I was giving her too much codeine. They said one or two pills every three or four hours and we started off with one but soon she was asking for another so I started—oh well, it says two pills so I gave her two

pills—well within a day [nervous laughter] she didn't know where—she thought she was in the front room, so I talked to the health nurse and she said, oh no, cut it back a bit.

R Um hum.

Jennie So we cut it back and of course, it cleared up. We didn't have any problems after that except for the fact that recently she's taken more and more codeine all the time and—so then Dr. R_______ just changed her on to the morphine base. So maybe that's the same thing. I'll just have to—

R Um hum. Just kind of—

Jennie Yeah.

R Try it and see how she does. But really that kind of does leave all that up to you doesn't it? To make those adjustments?

Jennie Well, in a way—

R With medication.

Jennie I'm here twenty-four hours a day practically so I can see a change in her more readily than anybody else. Like see, Laurie hadn't been here for about two days and Laurie was so surprised that she was so groggy today. So she left word for me to call and I called and she said well maybe it was a bit too strong, maybe I should cut it back a little.

R Um hum.

Jennie So that's what—

R What you've been doing?

Jennie Yeah. But, you know, it must be hard for someone, like for instance, Laurie, who comes maybe three times a week. There will be three or four days where she doesn't see her so—of course, it would have to be more up to me to—well I would see sooner what the effect of this is, you know. (Getting the dosage right) (3:2:1,2)

Jennie Like whenever we get a prescription we would get 60 codeine pills. Well she was taking an average of six a day so that would be ten days worth. But then it happened that her pain must have gotten a bit worse and she was taking a little more and as it happened it was a long weekend and I counted them on Thursday and we had 35 pills and we thought that would be enough to get us through to Tuesday. Well, it didn't and she had more pain and we used more pills, so Monday it comes and there's only three pills left. Like we're panic stricken. [Nervous laughter]

You know, what are we going to do? So I phoned my doctor's office and they had a pager and it did get hold of a doctor and as it was the health nurse was here, so I had the health nurse talk to the doctor . . . But in order to get codeine, you have to have the prescription, the written prescription from the doctor. You can't get it by the phone. So this Dr. C_______ said she would phone a drugstore and I suggested Boots because it's always open. Well, it wasn't open. [Laughter] So anyway, she did phone it into Guardian Drugs and they were good enough to let us have a prescription of a hundred codeine pills if, on Tuesday, I went to the doctor and got the written prescription and took it to the drugstore. But as it was, Tuesday I had to write an exam. Wednesday, I didn't have anybody in the house to look after grandma and the baby while I went, so the drugstore phoned and I can see their dilemma.

R Yes.

Jennie So, I mean you just don't hand out pills to people so I had Theresa take the prescription to the doctor—like take the form stating that we had got the prescription to the doctor and she would give a handwritten prescription which would have to be taken to the drugstore so that they could have a record that they indeed did have a prescription for these 100 pills. But you know, even grandma, she knew there were only three pills left and its' worrisome to her and I know exactly what she feels like because I had asthma and if I missplaced my ventilator or anything I would get really, really worried that I might have to go through some period of discomfort and, you know, fortunately everybody [cooperated]. (Obtaining enough medication) (3:1:23,24)

Jennie needed to be inventive when it came to other home nursing skills.

The Need for Equipment: The Need for Information

Jennie . . . she liked to be up and of course the hospital bed just made it so easy and then, as well too, another thing, when we would get her all up in these pillows she would tend to slide down. Well with the hospital bed you can turn the feet up a tiny bit so that her feet are up and it prevents that sliding down business.

R So it was much more practical toward the end.

Strategies for Coping: The Need for Information

Jennie Oh well, you should have seen what we had to to do to get her up [laughter]. I said to Louise one night, if anybody ever came in here and saw me, but you know if I were alone and grandma got slid, you know, down into bed, I could hardly pull her up so I would take my shoes off, get up on top of the bed and straddle her and I'd bend over and I'd say, you put your hands around my neck, and I'd grab her like this and we'd go ooph. [Laughter] And I'd say, good God, if anybody was looking through the window [laughter] they'd wonder what on earth I was doing to her. But it just came down to that's the only thing I could figure out. [Laughter] She thought it was quite funny too.

R You get very ingenious.

Jennie Oh yeah. [Laughter] In fact, I told the kids about it, I thought it was so funny but, anyway, one time when I had gone out, they resorted to doing this too. (3:4:26)

Family Caregivers' Perception of Home Care Assistance

Before the family got into a familiar routine with the proper equipment, physical care for Mrs. J was very difficult. Jennie could not believe the difference proper equipment would make.

Jennie	Well so far as—gosh, you know having a hospital bed here is marvelous because we had twenty pillows propping her up before and now we just crank the bed up and she's got two. But before we used to spend half an hour adjusting the pillows to get her comfortable.
R	She seems so comfortable [now].
Jennie	She had bedsores and now they've got them all cleared up with various things that you—the sheepskin, lying her one side and then the other and then they put some of that plastic that's just like skin, I think they developed it for burn victims. They used that and—they tried many, many different things before it finally worked and they could clear up and, you know, having these pads delivered when we need them and all that type of thing. Then they gave us a slipper bedpan now because she's really getting so tired that she doesn't feel like being hauled out of bed every time. And I think there's a lot of pressure against her bladder, probably from the tumor that makes her feel that she has to urinate a lot. So now having this little slipper bedpan helps a great deal. You know, you don't have to haul her out of bed and haul her in and get her comfortable again. So, you know, as far as help like that, I couldn't ask for anything better. Laurie's just been fantastic. Anything that she thought we needed—(3:1:25,26)

The Fatigue of Caregiving: Overload from Multiple Stress

I had noticed a nervous quality to much of Jennie's laughter. I asked her if she was able to sleep. Jennie talked about her fatigue and then tried to make light of it.

Jennie	I don't—I don't sleep deeply. I think it's because I'm tense. A couple of days here, I had kind of a little nervous problem. And I think it's because I know I set the alarm that I'm going to be getting up and so probably I've already made up my mind that I'm not going to go to sleep that soundly. But when you do get exhausted you really pass out. But—see mine is not an ordinary—I have extenuating circumstances. For instance, I'm looking after my grandchild. . . . (3:2:3)

Later:

R	When you said your nerves . . . was it physical illness or did you just really feel—?
Jennie	I think I just got so over-tired and with this thing of the house selling and all of a sudden now I've got to look at some property. Like there are extentuating circumstances that other people wouldn't have.
R	Um hum.
Jennie	And so then I rushed out on Sunday [to the acreage] and I loaded up a bunch of stuff and I probably exhausted myself. [Laughter]
R	It is true, though, isn't it, that . . . the rest of your life has demands?
Jennie	That's true.
R	They continue.
Jennie	Exactly.
R	That have to be attended to one way or another.

Jennie Yeah. See in my husband's case, there were funerals that he had to go to in British Columbia. In fact, he was crying when he left because she had one of her bad spells and he didn't think—he thought she might be gone when he was away. And he was crying when he left. (The other demands on caregivers) (3:2:4)

He was, you know, he was all right after a time. But it's true, life does carry on, for instance, this morning I gave her that medication and I just got back into bed and I thought oh, if I could catch two hours of sleep before the baby wakes up I'll be doing real good. Then she rang and when I got there, I said, you know, what would you like? I was having a dream. And I said, well is there anything you'd like. [Laughter] So I said I'm going back to bed grandma. I trip off to bed. And I'm no sooner lying down and thinking, ah, it's so nice and ding, ding, ding [the bell again]. [Laughter] And that's when you feel this ahhh, welling up in you. [Laughter]

R Wishing there were three of you.

Jennie Yeah. [Laughter]

R One that could sleep.

Jennie Exactly. And that's when you're not quite as sympathetic or as loving and caring as you should be. [Laughter]

R Find out you're human too?

Jennie Oh yeah. You better believe. (3:2:5)

I thought of the large extended family of Mrs. J and asked Jennie why she thought that it was she who became the primary family caregiver? Jennie ran through the possibilities but ended up by saying:

Jennie But then I have to be because the other girls all have jobs.

R Um hum.

Jennie And of course, my husband he has to keep on with what he's doing. So naturally—

R It falls to you?

Jennie Yeah. And as I say, probably if I were working a person couldn't do this. But I got my—were you here when I wrote that dumb accounting exam? [An abrupt change in topic]

R You were going to. Did you get your results?

Jennie Oh I was in such a flap that day I went to write that exam. I was so tired I could barely walk down the street. I could hardly keep my eyes open. [Laughter] But I didn't sleep the night before but I—I said, oh, I've got to rewrite that exam. I botched that exam. I'm just going to do horrible. I didn't finish it. I was that much from finishing. So I got 93.

Jennie talked a little more about her own future career but ended by saying "I think that one thing you learn to do is not to plan too far ahead. And not to worry about it" (The future is put 'on hold') (3:2:6).

Although the following details may at first reading appear to be small details, even trivial details, I found that the caregiver's experience is filled with "small" successes and failures. These small details become relatively large in importance when put into the caregiver's context. They are therefore explored with the caregiver and reported.

R Are you still making those special treats for her? The last time I was here you were cooking fresh carrots and enticing her [to eat].

Jennie Oh she, oh she hardly eats anything but until maybe three or four days ago she was taking her cream of wheat just about every morning. Very seldom she ever turned that away. But she might take a sip or two of soup or a couple of spoons of jello. I gave her some mashed up pears and juice that she really—she always liked, and after she had it she said it made her feel bilious. That is the word she used. And so they told me not to force her to eat. Just make sure that she had lots of water.

R Um hum. And ice—

Jennie Ice. She loves ice. In fact Theresa brought me some little bags of ice cubes, just the right size. Here I was, you know, what a dummy. I could have gone down and bought—of course, you see, we don't drink so I've never been a big ice keeper. [Laughter] Isn't that funny. Just the perfect size of ice cubes. Here I was freezing it in the little plastic thing and banging it away to break it up and it was either too big or too small—

R Or sharp edges or—

Jennie Yeah. And here Theresa came two mornings ago with bags of these perfect little ice cubes like this.

R It's worth knowing.

Jennie So it's just perfect now. And she can have her little cup of ice and take it as she pleases.

R Um hum.

Jennie But as far as the eating, she's just—what did she have today. She had maybe three sips of bouillon and taking about five minutes in between each sip. So then I put an orange into sections and she had maybe three sections that she just chews—swallows the juice and spits out the remains, the pulp and that. But other than that she hasn't had anything. Other than juice—ice cubes and water. And I tried clear apple juice and she said that's too sticky. I tried that white grape juice.

R Um hum.

Jennie I tried ginger ale. She just doesn't want it. . . . she frankly has told me she's just not hungry. (About nutrition: Trial and error) (3:2:16,17)

There is another reason for dwelling on the patient as well as continuing to focus on the experience of family caregiving. Mrs. J maintained her personality and her dignity even though much of her physical care involved rather undignified procedures.

The Need for Information: Physical Care of the Dying Patient

There is a temptation to bypass a few pages of data that deal with the physical care of Mrs. J. I would like to spare the details to spare the reader and the researcher the indelicate part of home care. However, I believe that a less than realistic idea of home care for the dying person would then be portrayed. Professional nurses like myself tend to forget the number of tortured oranges we demolished as we practiced giving injections. We don't recall the fear and trembling with which we approached our first patient with an enema tray. Hearing about the physical caregiving first hand from Jennie and then from George made me realize something of twenty-four hour a day, seven days a week caregiving that is expected from the family caregiver in the home. At home there is no hospital routine and no professional personnel to mask the reality of caregiving to a dying person.

Jennie talked further about some of Mrs. J's physical needs that she found herself coping with in the best way she knew.

Jennie	. . . problem that someone like grandma has is dry mouth all the time.
R	Um hum.
Jennie	And Dr. R_______ was in this morning and she suggested a negulous something or other.
R	A nebuliser?
Jennie	Nebuliser. And—but Laurie wondered if it wouldn't with all this moisture, if it wouldn't make more of that clear phlegm—
R	Mucous.
Jennie	Yeah. She's always had that problem. Sometimes two or three times a day we go through a period of when she has to cough up this clear mucous or whatever it is. And that can be a fifteen minute procedure.
R	Um hum.
Jennie	Because she'll cough it up and then she'll rinse her mouth with water and then that'll bring up some more and she rests for a while. [Laughter] So it does take time. It takes time to—
R	How is that for you? Are you—do you sort of feel yourself—
Jennie	[Laugh] She said to me one day, I was busy drinking my tea, my close companion, and she said to me "how can you drink that tea?" [Laugh] I was listening to her go through this. [Laughter] But, I think if I were younger it would probably make me feel nauseous.
R	Um hum.
Jennie	But then you must remember we farmed [laughter].

R Yes.

Jennie And I ended up doing things that I never thought I could possibly ever do.

R Good preparation?

Jennie Yeah. [Laughter] And, you know, I've had to do some terrible things on the farm just out of necessity. (3:2:18,19)

I hadn't really sat down and thought about it but [pause] I've had to wipe grandma's bottom and if you thought about it beforehand it would probably put you off. But when it comes right down to it, it's not all that bad. [Laughter]

R Like you have to—

Jennie Yeah.

R It has to be done and so you do it without maybe thinking about it?

Jennie I think it's just that it has to be done and so you do it and then it's not quite as bad as—I mean, what the heck. You know. I shouldn't tell you this, but it's true. [Laughter] Oh gee. She had an enema one day and the stool would not move and she was sitting there and she was trying—she was rocking back and forth and trying to get rid of this stool and she said to me could you press it, could you, you know, do anything. Well I finally used my finger to remove it, because what the heck, you can't—you know and if someone had ever told me that I would have done that I would have said, ahh. [Laughter] You know. (The reality of physical care for the dying patient)

And then, of course, I'm not a nurse. Maybe a nurse probably wouldn't think anything of it, you know. But—

R You just—

Jennie It had to be done and you couldn't let her sit there and be in misery like that so—I never told my husband. I didn't know what he'd think. [Laughter] (Family caregiver required to act instinctively)

R Um hum.

Jennie But afterwards I thought, gee whiz, you know, I did that. [Laughter] But you know I was such a—when I was young and when I was first married I couldn't even stand to handle raw liver. I was such a persnickity person about things and—

R Um hum.

Jennie It's funny how you change. (Responding/hands on care—changes family caregiver) (3:2:20)

The Patient's Need for Touch and the Caregiver's Response

The other physical need that is sometimes thought about particularly in hospice work and in the literature of psychology is the need for touch (Levy, 1973). I hadn't asked the question about touch but Jennie thought that it was important enough to make the following comments.

Theresa, the homemaker, had commented on Jennie's devotion to Mrs. J.

Theresa I always look at Jennie and I wonder, would I be like that?

Would I look after my mother or would I look after my mother-in-law?

Jennie I wonder if my kids will look after me. [Laughter]

Theresa You wonder if our kids would look after us. I hope that they would want to. (Reciprocity)

Jennie I have a notion that they would. Mostly because I see them helping here and I think they would. And you know, even my son-in-law he's twenty-five. He plays in a band [laughter]—

Theresa Cool.

Jennie Cool. [Laughter] He will lift her out of bed. In fact, she's got quite a thing for him. [Laughter]

Theresa She keeps saying how wonderful he is and you know, she says, "He's quite a boy, that boy." (Patient appreciation) (3:1:7)

Jennie You know the thing I just thought of too is in the beginning, when she knew she had cancer. It's almost like leprosy. And I think the fact is that people don't mind—you don't mind putting your arms around her to lift her. It's not like she's got some terrible thing that you're afraid to touch her. Because I think if you were like that you would probably make her feel like she was dirty or had some terrible thing wrong with her.

Theresa She was like that with me at first.

R Was she?

Theresa You know, she didn't think that I should have to, like touch her—I can't remember what things she had said but . . . it was just the first few days, she really didn't know how I would react or how I felt. (About touching her and doing personal care) (3:1:19)

Jennie Before the hospital bed came too, sometimes if I were tired I'd just lay down on the bed beside her and we'd talk or I'd have the baby. She really enjoyed the baby. I think that was—I mean if she's up in heaven remembering, I think that's one thing she'll really be grateful for is having the baby there. One of the funniest things that was to happen was I put the baby up to her one day and I said to baby, give grandma a kiss. Well the baby licked her twice and grandma licked her back. [Laughter]

R Communication.

Jennie   A little licking going on. [Laughter] My husband kind of frowned because he doesn't think that's very hygienic. (Infection control not perceived as problem) (3:4:25)

I had noted that Brandy, Mrs. J's rather stiff-legged old dog spent a lot of time in Mrs. J's room; even on her bed. I had commented on Brandy.

R   Brandy spends quite a lot of time in grandma's room.

Jennie   For many years, grandma always had a big chair with that foot stool and the dog always kept one hip warm.

R   Is that right?

Jennie   Yeah.

R   So they've been old pals.

Jennie   Old friends. Yeah. (3:2:10)

Jennie went on to talk about pets and suggested that people could possibly live longer if they had a pet to care for. Jennie thought that Brandy's presence was good for Mrs. J because George's family was "not a very hugging family" (3:2:11). Things had somewhat changed because now Mrs. J would "kiss and hug me when the spirit moves her" (3:2:11).

Reflections on Touch and the Caregiving Experience

I thought that it was unlikely that 'Brandy' would have been welcome in most acute care settings and yet she obviously brought comfort to Mrs. J. I thought back to Jennie and the baby stretching out on Mrs. J's own big double bed before the arrival of the hospital bed and again it occurred to me that this whole caregiving experience is a series of trade-offs. Give and take. Family strengths and family deficits.

Jennie sometimes wondered about the cancer and what it was doing inside Mrs. J's body.

Jennie	Well, in the beginning, when she was first ill, we would have to go through that experience of taking her to the doctor's office, etc., etc. because they didn't know—she was quite well really.
R	And able to—
Jennie	She could function at home for—she had this problem of vomiting which was, of course, the cancer pushing the stomach out of whack, I guess. (3:1:15)

And later: "And I'm wondering if that's what the mass is doing now" (3:2:18).

On another occasion Jennie thought that Mrs. J must feel like she had her stomach stapled shut and "there was the odd time when grandma turned yellow and we didn't know what was happening" (The family caregiver conjectures about 'what's happening') (3:1:11)

The Support Matrix Assessed

Jennie relied on help to manage:

The doctor makes house calls:

Jennie:	[When grandma turned yellow] the doctor was there in a couple of hours . . . knowing that the doctor will come if you need a doctor is good. (3:1:11)
	Just to think, [without house calls] if

> she needed a doctor you'd have to get her out of the house and—that's what we found difficult when she first became ill.
>
> . . . when I was small, the doctor came to the house. Well it [usually] doesn't work like that any more. But, you know, grandma was—she had an obstruction and I had to take her up to the doctor's office. She had to sit and wait. She had to go up in the elevator. My husband supported her on one side and I on the other and she kept "Ohh, ohh." And then we had to take her over to the hospital for x-rays. It was very, very hard on her. (3:1:12)

Jennie talked about other sources of help:

> Jennie In a way I am fortunate because a lot of people couldn't do it. There's just no way financially or any other way. But I can do it. You know, with the help, like my husband, the children and Theresa and the health nurse comes in once a day and they said, you know, if it got worse, they'd even have a health nurse come twice a day. (3:1:11)

Jennie frequently talked about Laurie, her home care nurse and about Theresa, her homemaker:

> Jennie I think knowing that the health nurse is going to be here every day and that I can lay on her anything that's happened. Like that she didn't eat [nervous laughter] or—and to be reassured. I think this home care thing is—I don't know how we would have done without it, to be quite frank. Because it's sure supportive, very supportive. And having Theresa here, knowing that those two days I can get out or I can do something, like for instance, write this exam and I don't have to worry about anything happening at home. (A flexible homemaker and daily help from health nurse are essential) (3:1:22)

Costs and Benefits of Well-Developed Support Matrix

Debbie, Jeannie's youngest daughter, came in from school while we were talking:

Jennie	So how'd your [school] pictures go?
Debbie	Mom, I only got my ID pictures taken because I never had $8.50, which is more money I have to pay. And I saw the T-shirt that I want.
Jennie	Hmmm.
Debbie	It's a Springsteen . . . sweat shirt.
Jennie	Write it down on a list. [Laughter] But anyway—
Theresa	And put it on the fridge.
Jennie	Even Debbie has lifted grandma out of bed. She's strong. [Laughter] But I think— I would say in total that the whole experience has probably been good for the whole family. Wouldn't you think? (3:1: 12,13)

This household too was lively: much coming and going and demands on Jennie. It was obviously "good for the whole family" but Jennie, like Joe and Salim, lived in a "pressure cooker" environment. It appears that there is a cost as well as benefits to having a large extended family to help with the care of the dying patient. The daily needs of a grandchild, for example, were described by Jennie but not until after Mrs. J's death:

Jennie	You know, when you go to bed at ten o'clock, you think well two o'clock's the next [laugh] and—but having the baby I think made it probably a little more difficult because quite often I would think to myself, well, if it was just grandma I could sleep

> during those four hour periods, like even during the day, I could lay down and sleep but quite often the baby's schedule and grandma's schedule weren't synchronized [laughs] so I'd just get one down and then the other would be up. In fact, grandma did say to me one day that I had two babies.
>
> But, you know, perhaps someone else in our position that didn't have a baby at that point, it probably might be a bit easier. (3:4:3)

The Difficulty of Extending Emotional Support to the Patient

Jennie talked about the constant demands on her time in this large active household:

> You know there are times when a person feels a little short with her, you know, at five o'clock this morning, she took a pill and I just got back into bed and at 5:30 she rang and she wanted a pillow out under here and at that time I do admit, I'm not—I don't carry on any great conversations. [Laughter] . . . I know what it's like to be very, very uncomfortable and to have to ask—to depend on someone to help. (3:1:21.22)

Jennie had mentioned that at times she felt guilty about not being available for Mrs. J. On the following visit I asked her about "feeling guilty." Jennie said:

> Well, for instance this morning . . . apparently she would probably have liked to talk. She said wait a minute as I left the room and I said I just have to get some sleep. And then of course when I lay down I think, aw, what a ummm.
>
> What if I were in—yeah, what if I were in that position. (Guilt) (3:2:5)

Jennie later in the interview gave me another example of too many things to do and how difficult this preoccupation with "other things" is for the bedridden patient:

Jennie It's just too bad that so many things happen at one time. For instance, now I've started looking for a house and of course that boggles your mind. [Laughter]

R A big decision at any time.

Jennie And I hated running around looking at all these places.

R Time consuming

Jennie It is and it's tiring too. And not only that, wondering what on earth you're going to do. Whether you're going to end up buying an acreage, whether it would be better to sell the house here and get another house or fix the house up we have and stay there. You know so your mind's going around on that level and I did the stupidist thing yesterday—or—I think it was yesterday. I went into grandma's room and I said, I'll get you some ice and some oranges. She likes the orange sections.

And then I came out and I was going out to do something and some of the kids were going to stay here for an hour while I went down to the mall for something. It just completely slipped my mind that I had forgotten to give her the ice and the orange. Anyway I guess she laid there and waited [laughter] and nothing appeared. So Debbie said I went in there and she said—and she very seldom ever does this—she said, I want my ice and I want it now! [Laughter] So I said to Debbie—Debbie got a little perturbed—well it was really my fault because when I left the room I said that I was going to do that. And can you imagine if you were bed ridden and you wanted something and someone said I'm going to get it and then never show up. [Nervous laughter] (Forgetfulness)

[Laughter] I never even thought of that until I came home. She told me and she told me what happened. I thought poor grandma, she must have really thought that everybody ran out on her. [Laughter] And to tell you the truth that's the first time that she's ever said anything like that. (3:2:14,15)

Jennie reflects on the caregiving experience for other members of the family:

> I think sometimes—well, the oldest daughter, she took on quite a bit of responsibility. She made sure that there were weekends that she came and took over completely and that we got away. Because it was during the summer months and our summers are so short, there probably was a bit of resentment that you just couldn't help.
>
> Because they probably felt like, oh, we're stuck here in the house, why couldn't we be out at the beach? Or—you know, we've got a boat—why couldn't we be out boating? And I think that's only normal. Probably because my husband and I were older, we were more able to say, "Oh we'll take, you know, just a day at a time" and after certain—you know, "this will only last to a certain point and then we can carry on with our lives." But I—Debbie probably felt put out a bit too, you know, because she was probably in the background.
>
> And I think probably because I had the baby and grandma that Debbie was probably in the background even more so. She tended to go in the basement in that bedroom there and spend hour after hour by herself. It probably wasn't very good but—I mean, life's not perfect, you know, we all have to take a back step once in a while. (Burden to other family members) (3:4:3,4)

Expectations of the Health Care System

I asked Jennie to explain further her expectations of the health care personnel.

Home Care Nurses:

Jennie It's been really quite important and personally I'd like to give a gold star to home care nurses. For one thing, one of them lives close by and she gave me her number and said if any time you need me, give me a call. And then Laurie too, has given me her home number. For instance, if I couldn't have got codeine, the first person I would have turned to would have been Laurie. And it gives you a sense of security

> that you know you've got someone to—
> someone that's got some authority to do
> something. (Security) (3:1:26)
>
> I wonder if it would have been that way if
> I hadn't had the health nurse here to talk
> to the doctor. You know. If I had just
> phoned and said my name is this and this and
> I need this codeine. I wonder if it would
> have worked.

Jennie was referring to the holiday weekend when she had needed an emergency supply of codeine. Jennie explains further:

Jennie	Because I don't feel like, for instance, with the drugstore, I wouldn't have any authority, you know, to get anything to help grandma if something did happen. Just having someone to turn to that you know can help makes it easier. (Authority)
R	[And as you had said previously], not that you would need to or not that you would think to use it unless it were an emergency, but it's just that kind of backup—
Jennie	Yeah. Exactly.
R	That gives some sense of security.
Jennie	Yeah. You know, for instance, if this codeine all of a sudden didn't work for some reason or other and she got into a situation where she had terrible pain and there was nothing I could do, I have a few numbers that I could call and I know I could probably get someone over here in a short period of time and I think it's fortunate in the way that I live in ________ with things close by.
R	So help isn't any distance at all.
Jennie	It's the same with my father. You know he had terrible heart attacks and they would always be in the middle of the night or the early mornings and my mother would phone and in five minutes they would be there and— Oh, for my mother it was great, because like,

you know, when my dad would have these and it felt like his heart—his chest would burst open they were so terribly painful and to be a person not being able to do anything is a terrible position to be in. (Availability) (3:1:27)

Jennie sums up her satisfaction with the status quo:

Jennie But I know today, in today's society, your physical needs are actually looked after mostly I would say, you know. Like grandma in this case could be hospitalized probably and all her needs taken care of physically.

You know. But you can't expect an institution to take care of everything. (3:1:18)

I pursued this comment further at a later date. The transcripts are from (3:4:27,28,29) which was the last visit one month after Mrs. J's death.

Home Care vs. Hospital Care

R Can you tell me more about that? What is missing [in hospital] that you could provide at home?

Jennie I think what I worried about, I worried that we couldn't look after her as well as maybe they could in the hospital. But then my idea of being in the hospital is if for instance, if I had asthma and had to be hospitalized, then they would look after me. They would give me the proper medication or oxygen or—you know, the things that I needed.

And not only that, I wouldn't have to worry about the kids, you know, I would just be there to get well and so when I think of a hospital, I think of it in that regard. But to go into the hospital to die, I think is a completely different thing. I was always going to the hospital to get better. I think it was always on my mind that maybe we couldn't make her as comfortable maybe as a nurse and maybe that's why it was important that a health nurse come every day towards the end. 'Cause I used to ask them questions or, you know, I'd—they'd say, how is grandma, and I'd give them a rundown on when her medication was, what she was like, etc. etc. and they'd give suggestions or say, oh well, that's the way it's going to be.

Or they'd tell us what to expect and so the health nurses come was just really— (Reassurance)

R So they gave you reassurance and—

Jennie Oh yeah.

R And advice?

Jennie Yes.

R Was there anything more that you would liked to have had from the nurses on looking back? Could they have done anything more, anything different? Were there any gaps?

Jennie Basically, I'd give them 100%.

Because I thought they were marvelous. And grandma did too. She really—she just really thought they were great.

R How about, we were talking before too about the continuity, the idea of having one homemaker, one nurse, like your nurse, your homemaker? Can you tell me a bit more about that. You [had] said it was important.

Jennie Well I think with having Laurie, I knew Laurie kind of ran the show. But as far as having the other nurses, that was fine because we got to know them anyway 'cause for two and a half months there are only so many and so when another one came, you know, they'd—you'd introduce them and then a week down the road they might be back. You got to know them anyway. So I think as far as the health nurses go, it wasn't— and then Laurie made sure she came once, twice, three times a week and Laurie too planned out when, like two tub baths a week for grandma, two enemas a week for grandma, and which days they were to take place and Laurie made sure that she came to see what was going on and how things were progressing and so I appreciated that. As far as the homemaker goes, I still think I appreciated having only one homemaker because I got to know Theresa. In fact Theresa and I are going out Thursday for coffee. (Someone in charge)

So [pause] But having someone come into your house and make your beds and do your laundry and clean.

R Did it feel like a bit of an intrusion of your privacy?

Jennie It did in the beginning but then after a while I kind of got—she didn't care and I didn't care. Maybe if she's been a different type person, it would have been different but she's quite easy going. We had our own little thing there.

There were days I was late and days she would have something and we kind of worked out—

R Your own routine between the two of you. She was flexible?

Jennie Yeah. Yeah. (Flexibility appreciated)

R She also gave you some good advice. I remember the ice cubes.

Jennie Oh yeah. Yeah. She was always trying. And she'd usually phone on the weekend to see how everything was and if there was anything she could do and she offered to babysit many, many times for me, on her own time. (The importance of small details)

R So those extra things are really appreciated.

Jennie Oh yeah. I have to admit too, the health nurses seemed to be a breed of their own. I don't really know. I noticed that they all were hands-on to grandma and they would call her dear and rub her and, um, I think they were more personable. Maybe it's because you get to know these people better. I don't really know.

R How important was that?

Jennie Oh I think it's really important.

R   For you to see that.

Jennie   Oh yeah. Yeah. Yeah!

Death at Home

In our society dying at home is still not a common occurrence. Death at home is quite uncommon. I visited the night before Mrs. J's death when other members of the family were gathering. I visited as well five days after Mrs. J had died at home. The transcript of the homecoming serves to demonstrate the cozyness, the emptiness, the fears, the humour and the increased sense of family that such an event can provide. Because the transcript is lengthy and somewhat difficult to follow, I have included it as Appendix 8.

The re-telling of the 'death watch' is included in the body of this chapter. Jennie's reflections help us understand how difficult and yet satisfying it is to be with a person who dies at home with family nearby.

Reflections on the night Mrs. J died

Aunt Sara arrived Wednesday night. Friday morning at 2:30 a.m. Mrs. J died at home. Jennie told me about the death five days later.

Jennie   Isn't it funny that when you, someone is going to be leaving you, it seems to go on and on and on and then when they do, it's just like you run into a brick wall. Just bang. You know, I knew for three days my dad was dying in the hospital and yet when they came and told you, such a terrible shock.

Jennie But I mean, a person knew that—

R At one level.

Jennie Yeah. But just when they say that, it's just like you've run into a cement wall and stopped. You know, everything comes to a halt but—

Yeah. But it seemed so sudden when it happened and it wasn't— (The brick wall) (3:3:1)

I've thought of that [the strangeness of Mrs. J's death] often. And too, I always probably thought that I would be there when grandma left us and I wasn't. I was sleeping but my husband and Sara had sat with her all night and the nurse had just showed my husband how to inject the morphine. She came at six for the first injection and poor grandma, she just must have been tired right out because she really went into a deep sleep. They said the morphine would depress her respiration but I don't really think it did. It just seemed like it allowed her the rest that she needed.

I don't think we—yeah—I don't think we were giving her enough of that syrup. We were only giving it once every five hours and when Dr. R_______ came she said, oh, once every, you know, one or two teaspoons ever three or four. I think she felt that the once every five hours was too long an interval.

But anyway, so the nurse came at six and then she came at ten and my husband gave grandma the injection. She just watched to see that he could do it and then at two he gave her the last injection. But the one that—when the nurse came at ten, instead of giving the 10 millilitres, no, I don't know what it is, they only gave six because she had been sleeping so heavily and the nurse thought that she might not need quite so much.

But anyway, I guess she died about ten after two, shortly after the injection. But she had—I had been up to use the bathroom and

I heard, I heard what I thought was her calling Mac, Mac, but I asked my husband about it later and he said, oh it was just the sound of this breathing. I guess their breathing changes.

R Um hum. Yes.

Jennie And that's apparently what it was. But anyway, he came and got me right away and [pause] I wasn't afraid of her and I kissed her and I talked to her and then he asked about getting the kids up and I said yes, because I thought that they should be part of it too. (3:3:2)

R They had been a part of it all along.

Jennie Yeah. So we went down and got all the kids up and then he asked, you know, about the youngest daughter Debbie and I said, yes, you know, I think she should be part of it too.

And—mostly because it was something that I never went through as a child. As I said, I never saw a dead person in my whole entire life until I was 44 and it was something I always avoided. I avoided it at any cost because I didn't want to face that reality. And I think once you go through it then that fear is gone to a certain extent. It's not as bad as all that.

R [You] [the whole family] were part of all of it.

Jennie The nursing and the care—

R All the care giving.

Jennie Yeah.

R The heavy—

Jennie The weekends that they stayed so I could get out. Yeah.

R It's almost like missing—

Jennie The grande finale or whatever, yeah. I know that's—[laughs] (The family is awakened)

Jennie had been sleeping while Mrs. J was dying. I wondered how she felt about not being there after all of her caregiving. The subject was broached very tentatively.

Jennie I think the only thing that I felt is that my husband and Sara were there so—

R She wasn't alone.

Jennie Yeah.

R That's right.

Jennie It's the same when my father passed away. I could have been at the hospital but I had a sister that wanted—had brought some articles of clothing and they didn't fit and we spent endless hours at Kingsway trying to find something to fit her and in the meantime I kept feeling like, well you'd better get to the hospital, you'd better get to the hospital, and when we got there, he had had another heart attack or whatever and so we weren't allowed in but I saw my brother and sister were crying so we knew that he had had a bad time. And he had, just before the attack, I don't know if this is true because I'm not a nurse and I haven't had any experience, but sometime they say they start to feel a little better just before the end—

R Yes.

Jennie Well my dad had asked for the family and my brother and sister were the only ones, so they went in and he held their hands and he asked for tea and toast. He asked the curtains be drawn so he could see outside. He asked what kind of day it was and then he had this massive attack. But every once in a while, if you're not careful, you say, oh drat, if I hadn't have been with my sister, I would have been there with him. [Laughs]

But then [laughs], there it is again, how the mind works. (Recalling other deaths) (3:3:4,5)

Jennie continues to reflect on her changing relationship with Mrs. J:

Jennie	But the last two and a half months that I was here of course, she relied on me, I think, for everything and she appreciated everything that was done here for her and to me she became a different person.
	I really fell in love with her.
	And—I mean when I was younger there were times when I just hated her. I could hardly stand—in fact, I didn't speak because I got so angry but then I had to live with her too which is not very common these days. You know, they farmed and when I married and moved into the farm house. [Laughs] And there was such—there was such a generation gap. She was 60 and I was just in my 20s and I smoked and drank and all those terrible things and of course there was bound to be a lot of conflict.
	But fortunately it all worked itself out in the end. Towards the end we became quite close friends and she even thanked me for putting up with her son. [Laughs]
	. . . It's funny how life changes people and things. But too, adjusting to something—I'm actually glad for the two and a half months that we spent together.
	We resolved our differences during her illness. (Caregiving resolves differences) (3:3:7)
	Oh there were some days when I thought, how long can I endure this?
R	That's right.
Jennie	How long will this go on?
	But then the next day, thank goodness for the health care nurse and the homemaker, that I'd have an easy day and that seemed to—just was yesterday, you know.

Jennie And I got to sleep and my perspective—I'd regain my perspective again.

R But you had that time to kind of rework—

Jennie Resolve our differences I think.

R Resolve differences, um hum.

Jennie Yeah. And realize that I really did care for her you know.

A great deal in the end. (3:3:8)

Jennie continues:

Jennie I used to get really irritated with her over what I felt was her domination.

R Did you talk about it at all toward the end?

Jennie No.

R Or was it just sort of an understanding that you had without even saying that those things were—

Jennie Unimportant really.

R Behind you?

Jennie Yeah. No, we never said anything.

R Wasn't necessary?

Jennie No. All she said to me was thanks [laughs] for staying with her son all these years.

Yeah. But I think probably the most healing of all was for my husband.

Because they were alike in a lot of ways. They were both—she was a concert pianist and he actually should have been a writer but they're both the romantic, artistic dreamers. Up and down personalities.

And they hardly were in the same room before very long before they'd have a few words about something. [Laughs] But I think for my husband was probably the best thing that ever happened was to have been with her and to be able to look after her. To be able to care for her.

George's changing relationship to Mrs. J

R To have been able to give her that last injection must have—fe~~lt~~ that he was doing something a little out of the ordinary.

Jennie Yeah because the nurse said—that's another thing—the nurses are fantastic. She said at ten o'clock, she said, if you can't do this by yourself, she said call. I'm just down the street, she'd come over. [Laughs] But he was determined that he could do it.

R Um hum.

Jennie I mean if it—I dreaded the day that I thought I might have to. That oh gosh, I'll do something wrong. But anyway it didn't come to that thank goodness. But—

R Yeah.

Jennie I think it will help him. He won't suffer as much I think because he was able to help her in her need, in her hour of need, he could help her. And I think that's really something than to have just gone and watched her die slowly in the hospital without being able to do anything.

Mrs. J's death and its effect on the children

Jennie I think it was good for the kids too.

You know, like you can go through all of life without experiencing too much one way or the other. Like Laurie says the comfort zone. [Laughs]

R Yes.

Jennie Or you can mount some of these things and find out that they're really not quite as bad as you thought.

R You kind of find your own strengths.

Jennie Yeah. More or less.

Summing it up

Jennie Yeah. [Pause] Well you know if it came down to anybody, like for instance J____ phoning me and asking me if we, you know, if we thought in the long run it was the best thing. It certainly was the best thing.

R To have her die at home.

Jennie Yeah. (3:3:12)

Reflections on the night Mrs. J died: One month later

Jennie and I decided to 'get away' from the house for the final interview. We taped the following interview at SHU.

Jennie recalls the caregiving experience and Mrs. J's death:

> I think probably for that two and a half months because I was so totally involved with looking after her, that I seemed to maybe be in a bubble and then when she passed away, that night I cried but it was the next morning when I got up and I realized that she was gone and I'd never have to trot down that hall to that bell [laughs] that it really got to me. I just couldn't quit crying all morning. But, and then all of a sudden to be free kind of but not liking being free that much. Um, I can't explain it, I really can't. It's just a phenomena.
>
> Today, for instance, I was—I had a quiet day which is kind of unusual because we're busy moving and I thought to myself, you know, in a way it's pleasant. I've got time to play with the baby. If she goes to sleep I can catch forty winks. I don't have the other, you know, grandma's—thinking, oh well, she's going to be needing me right away kind of pressure that I had but [pause]—what can I say other than I miss—you know, I really did end up missing her. I think it's because for two and a half months I spent so much time with her that I got quite [close]. (3:4:4)

I talked about this phenomenon to another person whose mother had died after a lengthy illness. She described the feeling as "imbalance." The feeling she said was "like you have had a weight pulling on you and it is released but you are still pulling against it." This person knew exactly what I was talking about when I read Jennie's comments to her. "Imbalance" or "disequilibrium" was how she described this feeling of loss.

Jennie wanted to talk again about the night of Mrs. J's death. Although I had questions and an assessment form I wanted her to "try out" there was no doubt what was more important to Jennie.

Jennie reminisces: When Mrs. J was about to die, Sara had panicked and insisted that George call the paramedics.

Jennie Well see, like I wasn't there, but I did get up to go to bathroom sometime during that period and I heard grandma in the bedroom and I—I thought she was saying Mac, Mac, Mac and when I asked my husband about it, he said no, that her breathing pattern had changed.

And probably if I would have been there, I would have thought, we've got to do something, you know.

That she's suffering, you know, we've got to do something.

And I probably would have voted with Sara to call the paramedics. [Laughs]

I have to give my husband a great deal of credit. I really do. For carrying on. Because that's basically what she wanted. I mean, it was a goal that we had all worked for, to let her die peacefully at home in her own bed and to have called the paramedics and had her resuscitated, I think, we would have all thought we had failed somehow or other. (Having patient die at home is an accomplishment) (3:4:5)

Later:

Jennie At times I kind of wished my husband would have called me and at other times I say, hey, don't be so stupid. She has Sara and George there holding her hand and rubbing her arms and that and she was cared for right to the end so there's no problem.

To tell you the truth, when he first told me, I just didn't have any feeling. It's just like I was a blank. And then when I went to the hall and saw her, then I just had to kiss her. [Pause] What can I say? For all the fights she and I had through the years, that two and a half months healed that and I often, I often contemplate at night when I go to bed, if I—what would I have felt like if we hadn't had this two and a half months together. Would I have had a guilt trip because of the fights and the differences we had through the years. If we hadn't had this two and a half months—and the same for my husband.

I often wonder how guilty I would have felt that we had never been close but for that time had been. It's not that we never, ever had been close. We'd had our periods of being copesetic, but not really close and I certainly think that it helped my husband a great deal. (3:3:6)

[My attitude] started to change when she first got sick. Before her first operation.

R Did it?

Jennie Because she wasn't well. I had to take her to her doctor's appointments and she was always worried about getting there and we always kept saying, you don't have to worry about getting there. We'll make sure that we get you there, you know, we'll come into town. Like, at that time, we were living forty miles out so we always had to come in on those days. And I always helped her get undressed and helped dress her and—it was probably her own bearing up under all this that maybe I started to respect her more.

Or, you know, because I saw how she could bear up under all this—you know, being so sick and having to be undressed and dressed when she probably just felt like hell.

And not complaining. And I was there when the surgeon told her that she wouldn't—that he couldn't help her out anymore and I often wonder how I would have held up under those circumstances, you know. Would I have started to cry or what would I have done. But she never did. She always seemed to keep her cool and, you know, when I was younger, I didn't really think all that much of her. [Laughs] It's not funny. It's an awful thing to say but I think during that time I really saw that she was made of a much stronger fabric than I ever thought. I saw strength there that I had never seen.

R — And so you began to have that respect for her. (Change in relationship starts at diagnosis of 'terminal') (3:4:7)

And then as she became—

Jennie — Well, as she became worse and the more she relied on me, the closer I felt to her. It's funny that after she passed away we were all together that night after the funeral person had come to take her and then I looked at my oldest daughter and I said, well, the tyrant's dead. And we all started to laugh because we knew [laughs]—we all knew what we meant. (The tyrant's dead) (3:4:8)

Jennie and I talked further. I asked her, "How did you look after yourself or did you?"

Jennie — Well I think I always—if this would have been a reality, really long-term thing, I don't know how I would have done. To tell you the truth. But the way it was, I knew it wasn't going to be a long-term and if things ever got too bad for me I would say that this is only for a short time and you can do anything for a short time.

R — You tell yourself that?

Jennie — Yeah. If it would—if I would have had to project it too far into the future I probably would have given up or I don't know what I would have done. But like, right from the beginning they said that, you know, she probably didn't have too long and—although no one would say and I basically never really asked. I mean how do you say, well how long is grandma going to live? [Laughs]

But, you know, I knew that it wasn't going to be years that I was going to be faced with this, it was just a time, you know.

R — A time that you—

Jennie — Had this to do.

R — Could manage.

Jennie — Yeah. And I think knowing that I had Theresa those two days a week and the girls would help on the weekend. Knowing that I had breaks. Breaks coming up that you can manage.

R — So you can sort of go on very little sleep and irregular meals and—

Jennie — Oh yeah.

R — No recreation to speak of for a period of time, so long as you know that there—

Jennie — There's a break coming. (3:4:23)

Family Caregiver's Assessment Form

I wondered if the Assessment Form would be of any use. I had spent several hours with Jennie and thought that I knew her quite well. However I asked her to do an Assessment Form for me as a test of the form's usefulness.

Family Caregiver's Assessment Form

(Complete During Home Visit)

PROBLEMS FROM CLIENT'S PERSPECTIVE: (Circle appropriate words)

PHYSICAL:

Eating: too much/too little — lost weight

Sleeping: too much/[✓ too little]

Illness: actual/[✓ feared]

Energy level: reduced/[✓ increased] — sluggish — need to keep doing

Drugs: excessive alcohol/prescription/non-prescription

Pain/discomfort/tension: muscular/systemic

pulled muscle when lifting feared unable to carry on

Exercise/Recreation Yes/No- Why?

Comments/other: ulcers acted up during this time and had to take copious amounts of Maalox

EMOTIONAL: (Psycho-Social)

Isolation: lack of contact with others/painful contact with others

Crying: excessive/inability to cry — no - just the opposite

Fears: of madness/of [✓ breakdown]/of haunting memories/of the dying process

Dreams: pleasant/[✓ unpleasant]/nightmarish

Concern about ability to handle the situation.

Relationships: difficulty in maintaining relationships with family/[✓ with friends]/difficulty in coping with children's grief/[✓ difficulty in explaining death to child]/difficulty in controlling child's behavior

Too busy to keep up relationships with friends.

Would ask health nurse all necessary questions regarding medication, nursing patient etc.

Comments/other:

INTELLECTUAL: Need for information re: grieving/loss
- How to cope
- How to explain death to others
- Explanation of normal grieving

All needed

: dying process: pain control

Home nursing
- feeding
- toilet
- bathing
- turning
- medication
- giving needles
- bedmaking

: post-funeral questions - financial worries/concern with rituals or community expecations

Comments/[✓ other]:

Grandma's acceptance of her impending death helped us all.

SPIRITUAL:

Death - seeking to explain or understand death/doubts concerning after-death

Belief: other spiritual or religious problems/doubts concerning own goodness or self-worth/doubts concerning other's goodness or self-worth

Underlined belief in spiritual rather than material things.

God: doubts concerning the goodness of God/or the existence of God

reinforced religious convictions

Lack of meaning or purpose in life/No sense of personal future

Participating in what life has to offer rather than as onlooker

Comments/other:

The Family Caregiver's Assessment Form is very closely aligned with the original form developed by the staff at St. Christopher's Hospice in England. Jennie circled pertinent components and added her own comments.

Two items came out from discussion about the form. Throughout the caregiving experience Jennie was taking copious amounts of Maalox, a non-prescription drug for her ulcers. Jennie also used a great deal of Betadine as a disinfectant after working with Mrs J and before touching the baby. The adapted form is inserted in Chapter 5. The form may be useful in identifying family problems that would otherwise go unnoticed.

Jennie and I finished work at SHU and took leave of each other over coffee at the restaurant across the street. There is always a strange feeling at closure of the research relationship.

Jennie is about 5 feet tall and perhaps 100 pounds in weight. It seems incongruous that this tiny person could have accomplished so much.

Jennie at the end of our first interview had said:

Jennie There's a time to be born and there's a time to die. And you can't start playing games. That's the way people end up in the booby hatch. [Laughter] And you know, there's things in life that you have to accept and you end up doing some things in life that maybe you thought you never could do but you do them. And you feel better for it.

R Find your strengths?

Jennie	Yeah. I think you feel better for knowing that you can do things if you really have to do them. But—
R	Jennie, thanks so much . . .
Jennie	[Laughter] I don't really feel that I'm doing anything, that's the funniest part but in another way I feel fortunate that I have this experience. It is an experience in life really. (3:1:30)

Discovery by Comparison

Introduction

Nicole is chosen as key informant number four following the advice given by Glaser and Strauss (1967) and Glaser (1975). Glaser (1975:42) writes on theoretical sampling: ". . . differences do not disqualify a comparison, they enrich it. Comparing the apparently noncomparable increases the broad range of groups and ideas available to the emerging theory."

Nicole's story of caregiving to her dying mother is somewhat different from all of the previous informants' experiences. Nicole lives in her own home with her husband and young family and "runs around the block" to her mother's home to provide care necessary to support her mother's wish to remain at home. I believe though that the similarities of her experience with the other informants' experiences are evident. All informants live in a pressure cooker of multiple stressors, are tied to the past and old family relationships and are being changed for better or for worse by the caregiving experience.

Nicole's story is written in narrative style. Again it seems necessary to describe the other participants, particularly Nicole's father, the Brigadier, and her mother, Mrs. G. One absolutely certain piece of the developing 'theory' of caregiving for the dying is that there can be no separation of the caregiver's experience from the relationships with other family members. Therefore, the narrative starts with a description of Nicole's father.

Nicole

I met Nicole's father, the Brigadier, and Mrs. G at a cocktail party several years ago. Nicole was circulating there too but I hadn't met her. The party was one of those affairs at which you crush into people, make and take instant impressions then are moved on to the next "people you should meet." The Brigadier, "call me John" (which had the effect of my always thinking of him as the Brigadier), was a career military man. The Brigadier had gone to all of the right Canadian schools, had been "finished" at Sandhurst Military College in England and had, unlike Joe, made it to World War II, where he quickly rose through the officer ranks. The Brigadier, when I met him, was finishing a high-profile term of office for the Federal government and had somehow managed to keep everyone on his side, including the media. I had decided that

I would not be taken in but I found myself caught up in the Brigadier's considerable charm.

Mrs. G was even then waspish, meaning small and sharp-tongued. She circulated through the cocktail crowd measuring, calculating, looking around you as she was meeting you, then moving on to the next group.

The Brigadier died quickly and was buried with pomp and circumstance. Mrs. G died a more lingering death of cancer.

Nicole, the youngest daughter, was the primary family caregiver to Mrs. G although they never got along. Nicole had been her father's favourite and was just getting over his death when she found out that her mother was dying. Nicole told me about the occasion when Mrs. G had been decreed terminal and they decided to go out "somewhere and talk." Mrs. G booked a table at a small exclusive restaurant and Nicole dashed in late. She had fed her husband and three small sons before coming and did not look too well turned out. Nicole also picked at her food. Nicole never quite looked fashionable enough to suit Mrs. G and she always had "picked at my food" in Mrs. G's presence. Things changed but the relationship never did improve. That night was "a typical disaster," Nicole recalled. (Knowing you are dying does not necessarily change family relationships)

There really wasn't a choice about who would be the primary family caregiver. The eldest sister was working as a nurse in Toronto and the middle sister lived in Southern Alberta. Nicole was here. (The primary family caregiver is 'chosen' by default)

Nicole's husband and children had correctly cordial relations with Mrs. G (she was not the grandmotherly type) and they were not about to move in with Mrs G as Jennie and her family had done with Mrs. J. Nicole, when I first met her, was pulled between her loyalty to her dying mother and her loyalties to her husband and children. No one thought to mention that she could possibly have any loyalty to herself. (Role conflict of primary family caregiver)

Mrs. G refused to move. She lived in a large house surrounded by photographs and memories of a very exciting life. Mrs. G's medical contact was a general practitioner who lived across the street and a half-hearted liaison with Home Care. Always independent and somewhat prickly, Mrs. G did not fit well within the system. I can imagine the difficulty of the home care assessment of 'who' should help and 'how.' It was finally the pain that did it. Mrs. G admitted that she needed help. (Pain and fear of pain is overwhelming)

Mrs. G had been on "painkillers" and tried to lubricate the "break-through pain" with scotch. She relied on the general practitioner across the street and her daughter Nicole who came to stay whenever she could get away from her other responsibilities. Nights were particularly bad for both Mrs. G and Nicole. Nicole told me that she used to slip downstairs in the middle of the night so she wouldn't waken her husband or her children and sit wide-eyed, staring out at the streetlight wondering if she should drive around the block to see how her mother was doing. Mrs. G tended to spend the night on the downstairs sofa reading or upstairs watching whatever was on television. Morning was welcomed by both Nicole and Mrs. G. (Nights tend to be hardest)

I had heard about Nicole through a colleague who knew that I was "doing research" into the caregiving experience. I was to meet Nicole at Mrs. G's. A friend of the family let me in. Mrs. G was on the sofa, half drowsing, half looking out the wide picture window that opened onto a mass of foliage. She and the Brigadier had planted most of the trees. I could imagine why she would hang on 'tooth and nail' to this view. The family friend and I tried not to disturb her. After re-introductions (Mrs. G thought she remembered me), the friend and I sat and carried on a low-toned conversation while we waited for Nicole. Finally Mrs. G was exasperated and demanded, quite rightly, that either we stop talking or else include her in. (Misguided 'care')

We talked about the view, old times, etc., then Mrs. G talked about her many discomforts. She had dry mouth from the pills: I said that maybe unsweetened tinned pineapple chunks would help. She said how hard it was to get up to the phone which was across the living room: I suggested that 'we' get a fifty or seventy-five foot extension cord so that she could have the phone nearby. All of that advice could have helped but it would be Nicole who would have to "engineer" it. (Good advice weighs on primary family caregiver) However, it was really the pain that was first and foremost in Mrs. G's mind. We kept coming back to pain. (Pain is the most fearful symptom)

Finally Nicole arrived with her youngest son. He got sent upstairs to watch TV. This back and forth life of the primary family caregiver was having its effect on Nicole. Nicole told me later that the worst part of it all was the aftermath left by her oldest sister.

"The big noise from Toronto" is how Nicole described her sister. The eldest had been there on a two week vacation from her work in Toronto and had left much advice for Nicole to follow. I thought about how good it feels to be able to give advice. (I also remembered Joe and the weight of advice.) Nicole was now uncertain about what to do but knew that "this can't go on."

In conjunction with the home care nurse, the general practitioner and the Medical Director of the Palliative Care Unit, plans were made to find room at the Unit for Mrs. G. It was thought that there her pain could be better monitored and controlled.

These 'cameo' narratives are to be kept short so I will give only a few more details. One memory was my own fear as I backed out of Mrs. G's driveway.

Mrs. G had pulled herself up from the sofa and came to the door to wave good-bye. She was propped up on one side by Nicole and had a snifter of scotch in her free hand. I was, as was so often the case, torn between professional knowledge and a need not to be a "wet blanket." I thought of what could happen as Mrs. G unconcernedly mixed her "painkillers" and scotch and I also saw the relief on Nicole's face as she saw that soon Mrs. G would agree to be looked after. I did phone back to Nicole and kept close tabs until Mrs. G was safely admitted to the Unit.

The second detail is the story Nicole told me about Mrs. G running true to form in the Palliative Care Unit. Mrs. G kept two bottles of scotch in her bedside table. One bottle was top of the line, Chivas-Regal, the other bottle was nondescript stuff. Mrs. G was strictly off the scotch herself. It took some doing but her pain was controlled now. However, Mrs. G took some pleasure in offering her oldest and dearest friends a little Chivas-Regal when they visited. Some other visitors were given the nondescript. I will not swear to the truth of the second story.

Mrs. G of course had her ups and downs, but died somewhat in the style to which she was accustomed. Nicole exhausted herself running back and forth to the Unit but told me several months later that she is doing fine. Her eldest sister is having some problems adjusting.

Nicole Reflects on Caregiving Experience

Field notes from another visit with Nicole are helpful reminders of the various ways that caregivers deal with the strain of caregiving. The field notes are a collection of thoughts expressed by Nicole.

Nicole was unable to "really talk" to her mother who could be "so sarcastic." Every attempt to talk out unresolved feelings ended up in "our old battles." "Mom wouldn't even say thank-you for coming to help." "I'd come home and get mad at Ken [husband] and the kids." "It [dying] didn't turn her into a saint. She was always very demanding." "Mom had a lot of friends. I ended up putting my arm around their shoulders and supporting them." "I used to read a lot of books on death and dying when I couldn't sleep. I don't think that it made it easier. I still had to go through the feelings but maybe it helped me make something of it. It [caregiving] is sure a crash-course in self awareness." (Coping with the strain of caregiving)

Nicole reflected on something that puzzled her and made her feel somewhat guilty. "It's dad that I'm missing. We used to do so many things together. Mom and I have never been close." "Actually what I'm mourning is 'our old life style.' We'll have to sell the house of course, none of us can afford it." (Multiple loss)

A dying family member is not the only loss the caregiver experiences. Loss of past, present status, and wishful thinking about the future are some of the multiple losses a caregiver experiences. As Nicole said, "This is a crash course in self-awareness." I thought of Dabrowski's philosophical statement about crisis. Dabrowski once said: "Crisis is an opportunity for growth but it doesn't guarantee it." Nicole has "done well." I talked with her sometime after her mother's death. She told me, "we lost some family friends because we didn't mourn right. I'm afraid that my sisters and I started to laugh at something—I can't remember what—while we were being driven in the big 'limo' in the funeral procession. We wondered 'what would they think of us?' I suppose we were laughing with relief but I can't fuss about things like that anymore." (Caregiving is catalyst for change)

Bert

Introduction

Bert is chosen as the next informant. Chronologically, Bert was my last informant, chosen because he fell outside the Alberta Health Care System and I felt that I was becoming saturated with our local concerns. However, something even more instructive than my initial purpose began to surface from field notes made after my two visits with Bert.

Bert, a good manager and achiever in the business world, was so overwhelmed by caregiving for his dying father that he was at first unable to use the managerial skills that had served him so well in everyday life. The emotion he felt at seeing his father die and the family pulls and strains were stronger than his usual rational abilities that always made his world work. The image that remains of Bert is the dutiful son totally immersed in his father's care. On the side, he took runs at the system to try to make it work on his father's behalf. My field notes read:

> August 5, 1985
>
> Pain is the major theme that comes up again and again. Qualify of life isn't even an issue here. Survival is the one thing for both patient and family caregiver. Tenacity. Large family is a mixed blessing—conflicting advice. PAIN "I can handle the rest. I can't stand to hear him moan."

Bert is forty: a self-made man. Bert is a bachelor, the oldest son of a large Jewish family. Bert has had several careers and has been successful at all. He has the knack of getting into a business on the ground floor and riding the trend to the top. He then side-steps to another position with similar lucrative results. Even knowing him slightly, I find it hard to imagine Bert being at loss for ideas, ways, means to achieve his goals. However, his father's dying has been an extremely difficult 'rite of passage' for this accomplished man.

Bert's Family Background Described

To understand Bert's caregiving experience, it is necessary to consider his family. Bert's family had transplanted themselves at least physically from rural Russia to Boston a few years before Bert was born. Bert who looked and talked like a very sophisticated North American was, in fact, more pulled by family ties than was Salim whose appearance and language signalled "old world" values. Prejudging and instant diagnosis made on appearances would likely lead a visiting lay person or professional astray. (The influence of family 'culture')

Family birthdays, anniversaries, and other high holidays were celebrated lavishly with full attention to ritual and protocol. Bert, as the eldest son, flew home to Boston for most family occasions. Bert's father would not have been in Canada if it had not been that Bert was celebrating his fortieth birthday. His friends were planning a party for him and his father wanted to be here, in Edmonton, with his son on his 'fortieth.'

Bert's father was extremely ill, dying of cancer that had turned this patriarch of the family into a thin, bent shell of his former self. By rights, Mr. S should not have come for the party. He should have been home in the care of his daughter-in-law. As Bert said, "Hindsight is a great thing." Bert's mother had died not long ago and

Mr. S decided that family had to be represented at the fortieth birthday of his eldest son. Besides, as Bert said, "He needs to be social."

Bert flew to Boston to bring his father to Edmonton for the occasion. Mr. S was able to sit up for the flight although he was fortified with codeine. The stewardess had back-up oxygen. The trip was relatively uneventful.

However, two days before the birthday Mr. S "took a spell." He couldn't breathe. An ambulance was called and he was admitted to the hospital, all the while saying "I didn't want to spoil the party." Mr. S was diagnosed as 'heart failure' and the doctor did a good job of treating it. Mr. S was put on medication that seemed to solve the problem.

Bert recalled that his father looked better than he'd seen him for a long time when he was in hospital. He was always a "fastidious man," Bert said. "I'd find him all spruced up and joking with his room-mates when I visited. He always did relax when he thought he was in the hands of experts."

Bert told me that it was actually quite a relief when his father was in hospital. "I felt carefree; a real load off my shoulders." However, Mr. S was stabilized and it was time for him to come back to Bert's house.

As Bert tells it, "That's when the medical merry-go-round started." Home Care people had visited Mr. S in hospital to arrange services. However, when they found out that Mr. S was an American citizen, they couldn't help. Mr. S was beyond their jurisdiction. While Bert was still "unravelling the red tape" and looking at options, Mr. S returned home.

Bert as Primary Family Caregiver

Bert said, "In two days he [Mr. S] looked like a different man probably because he was so anxious. They treated his heart problem well in hospital but they didn't seem to be concerned about his cancer. We had to scramble to get more pain-killers because his supply was running out." Mr. S seemed to give up, at least in Bert's presence.

Bert's father was put on morphine syrup. "It was," Bert said, "like cough syrup, liquid and easy, very easy to use. He'd never say that he was in pain, but he'd moan. I can stand anything but I can't stand to hear him moan." Bert continues talking about his caregiving experience:

> He'd want to come out to watch TV with me, but he couldn't walk. He's not heavy now, but the only way I found that worked was to double the quantity of morphine syrup, wait a bit then lift him into my office chair and wheel him out. He'd stay a while, get uncomfortable, then demand to be wheeled back to bed. I handled him with kid gloves but he'd never even say 'thank-you.' (Need for information: Need for patient cooperation)
> (Synopsis from field notes)

All the while Bert was getting pressure from his father and from his family back in Boston to get Mr. S home. (Family culture)

Bert in one way was fortunate that he could afford to take time from his work. He had a very cooperative business partner and good staff to run his business. Bert was able to devote all of his time to caring for his father. I thought of Joe and his relief at getting back to his cockpit as a release from caregiving. However, I met with Bert only twice and I didn't feel that I could ask such an impertinent question as to his feelings about being 'free' to be always with his dad. We had not formed a relationship through which he would feel he could be totally frank. (Research role and its effect on data collection)

I'm not sure that it would have occurred to Bert to be a 'Care Manager' rather than a 'Care Provider.' He, in fact, seemed to take it for granted that he would do and be both care manager and care provider to his father. Some friends helped, brought food, sat with Mr. S while Bert went out to do the necessary tasks, but for the most part, Bert did the caregiving himself. One of his friends said to me that it was odd to see Bert doing housework, washing sheets, making beds, etc. because so far as she knew he had always had household help. (Care manager and care provider)

Mr. S was a difficult patient in some ways because he would not relax with Bert. Bert called it "The Prophet without Honour in his own Country" ~~syndrome~~. Bert, as he said, handled his father "with kid gloves" but Mr. S for the most part either criticized the way Bert did things or just moaned. When friends came Mr. S would perk up considerably and be quite sociable. When the friends left, Bert got the worst of it. (The difficult patient)

Mr. S kept up the pressure on Bert to take him home where he belonged. Bert's sisters and brothers in Boston were on the phone constantly trying to convince Bert to "fly him home." Patient demands and daily phone calls from the family added to the strain of caregiving.

By the time of my second interview with Bert he was beside himself with worry, frustration and fatigue. Bert, this urbane man who could ordinarily make the world work, confessed: "I'm just about beaten." The hospital would take Mr. S again but Bert would never forgive himself if his father died in hospital so far away from family. He somehow had to get his father home because 'home,' surrounded by family, was where Mr. S should be.

Bert had been making plans. Desperation drove away some of the confusion that had been immobilizing him. Bert went over his plans with me. There was a couple who had lived in his father's duplex for several years. They would come in when needed. The other family members would help and Bert would go and stay as long as he was needed. Bert asked me if I knew if there was Home Care in Boston. (One of the librarians at a local hospital found us the name of a Hospice program in Boston.) The entreprenurial Bert was back in charge in the service of family needs.

Bert had been trying to get his doctor to come to the house to see his father and prescribe "something," maybe massive doses of painkiller, to "sort of knock his father out for the trip home." Bert by now had given up trying to find private home help locally and was now totally focused on Boston.

Again, to shorten the story considerably, Bert managed to get his father home. The airline cooperated and Bert was able to sedate his father well enough that they made it with only moderate discomfort. Shortly after his return to Boston Mr. S died at home with the services of the community hospice program lightening the load on the family.

Bert is back in Canada but he has been in and out of hospital himself with "circulatory problems." Of course, one can never know whether or not there is any connection between Bert's health problems and the tension caused by his caregiving experience. I suspect that the strain has taken its toll on Bert one way or another.

Afterthought to Bert's 'Story'

Rereading the foregoing account made me consider a 're-write.' The words and flow are choppy and disorderly. The rapid pace was leaving me somewhat irritated. Things moved too fast. I would be trying to nail something down here and Bert would be riding off in another direction. But that is how it was. Geertz (1973) makes sense of it.

Geertz (1973:163,164) writes of the pull between the "urban" and the "folk" influences on behavior. Quotations from Geertz are selected as they apply to Bert's experience:

> Socially, his is a Gesellschaft [urbanite] existence . . . But on the cultural level—the level of meaning—there is much less contrast between the [urbanite] . . . and the villager [rural, folk]. The patterns of belief, expression and value . . . his world view, ethos, ethic or whatever, differ only slightly from those followed by the villager.

I believe that Bert's major tension was the pull between the "folk" and the "urban." The folk, i.e., family beliefs, expressions, values that 'we die at home with the family' and 'we do it ourselves' superseded the urban, sophisticated side that would have managed to get the resources needed to get the necessary help. It was not until Bert was able to turn the successful 'entreprenurial side' of himself into service of the 'family side' of his beliefs and values that things came together for him. (Family culture needs to be understood)

Summary: Plan for Further Research

Bert's story demonstrates the power of family culture. In studying the experience of primary family caregiving it has proven necessary to expand the focus of the study to include not only other members of the family but also the patient. If the patient accepts the fact of death and in a sense settles into it like Mrs. J and Nadia, the family can proceed more easily with the caregiving. However, if the patient is "difficult" like Bert's father and is pushing for a different place to die or "won't even say thank-you" then the caregiver has a more difficult task.

Differences in opinion amongst family members can have a negative effect. The example used in this study is Nicole and the "big noise from Toronto" who flew in, dropped advice and flew out. This gratuitous advice that conflicted with what Nicole could do, had a permanently negative effect on the sisters' already tenuous relationship.

Again, an inquiry of discovery pushes the developing themes further. The researcher looks for other situations, other people whose caregiving experience will teach us more about the phenomenon. Alice, who has allowed me to use her experience, had not only a difficult "patient" to assist but her family were in conflict about how to assist him.

Alice's Journal

Alice's journal is a collection of thoughts, letters and photographs about her involvement with her dying father. Alice is well educated, i.e., she has not only obtained the highest degree but has also experienced life's "slings and arrows" and somehow integrated it all into a person in her forties who is mildly ironic and extraordinarily kindhearted. She is also a professional caregiver.

I think of Osler's brisk analysis of the necessary credentials for professional caregivers. All that is needed, according to Osler, is a clear head and a kind heart. Alice fits.

Alice's journal is eighty-nine pages long. It is difficult to know how best to present her situation and 'the data.' Alice writes in a way that demonstrates that 'kind heart' does not necessarily mean soft and sentimental. There is an edge to her writing that shows very well the desperation people feel when faced with a dying person who will not become a patient.

Bert's father showed signs of being a difficult patient but Alice's father refused any intervention from family or professional caregivers. Although Alice's story is extraordinary, it does show how non-compliance of the patient (as it would be termed in the medical journals) plays havoc on the would-be primary family caregiver.

Negative cases, the antithesis of the ideal, may demonstrate again the reciprocal nature of caregiving. Alice's journal is excerpted to describe in chronological order her caregiving experience. The words are as Alice wrote them.

> Summary of Events and Persons Involved
>
> William Bailey [Alice's father], who died. (Age 66)
>
> Elizabeth Bailey, his wife, who, after 42 years of marriage, finally was forced out of their mutual home one week prior to William Bailey's forcible removal to [Psychiatric] Hospital. By this, I mean that she was unable to continue to live in this bizarre situation. She had a full-time job, but was increasingly disturbed nights by William Bailey's drinking, crying, and swearing. (63 years of age)

Georgina, the first daughter, who felt, right from the beginning, that, since he only had about a week to live, we should try to make his last days as pleasant for him as possible. For her, part of this was to bring him the liquor he requested. She acted out of her love for him. (41 years of age)

Alice, the second daughter (and writer), who felt, right from the beginning that there was no time to waste, fought for treatment, voluntary or imposed. It was at her request that William Bailey was taken forcibly from his home on February 21st to [Psychiatric] Hospital. (40 years of age)

Charlie, the only son, who, because his relationship with his father, William Bailey was already poor, and who was further alienated by an incident in August, more or less stayed back from the interaction, though he indicated that he would support Alice in her efforts to impose treatment, rather than Georgina, in her efforts to comfort her father in his last days. (33 years of age)

The split in the family regarding what was best for William Bailey added to the problem. However, in the final analysis, it did not interfere with the actions taken to have William hospitalized. His wife, Elizabeth, closest to this bizarre situation, initially took him liquor, but stopped when she realized that it impaired his judgment and prolonged the eventual date of treatment. It was she who stood before a judge in April and gave the evidence that was finally recognized, first legally, then medically, that William Bailey was a 'danger to himself'.

Dr. S_______, Alice's family doctor, who, of his own accord offered to go to the patient's home. Later, he signed Form 1 for admission to [Psychiatric] Hospital.

Dr. B_______, William Bailey's psychiatrist at [Psychiatric] Hospital. (p. i)

Summary of Events and Persons Involved

July. The carcinoma of the lip now apparent to family members.

August. William Bailey took to his bedroom, for good.

September. The two daughters discussed breaking the family rule and entering the room to talk to their father.

October. 1) The sisters approach William Bailey as planned. He tells them to get out.

2) William Bailey phones the second daughter (Alice) and asks her to come over. She goes to the home, and finds him coherent in a way that she never again sees him to be. He requests that she make an appointment with her family doctor, and she does. Several days later, in spite of the fact that he had been busy in the interim period getting his affairs in order and informing his wife that he would be "going away on business for a few days", he reneged at the last moment, and asked (still very much coherent) his wife, Elizabeth, to phone Alice and tell her that he couldn't keep his appointment because his stomach was upset and he thought he should stay close to home. Alice went to the house anyway, and, though he was adamant, refusing to keep his appointment, he did capitulate and agree to her making another appointment for a day several days hence. This she did. On this appointed day, he would not answer the phone or the door, once again in the depths of despair in his bedroom, and unapproachable.

November. William Bailey began to drink, heavily. Initially, his wife would get him liquor as requested. His first daughter, Georgina, did so right up to his death. His second daughter, Alice, refused to get him liquor at all, and begged the other family members to refuse as well, in an effort to 'flush him out of the bedroom'. By this time, it was obvious he was drinking to reduce the pain, as well as to keep from viewing the situation soberly.

December. The drinking becomes worse. Many nights he cried and moaned all night long, alternately begging to die and then making pleading noises for help. My mother, in the next bedroom, was becoming increasingly terrified of this man. Never physically abusive, he began, while drinking, to be verbally abusive, even assaultive, and began to wreck the house in small ways, e.g. brushing everything off the top of a desk, throwing food all over the kitchen.

January. I had been asking my family doctor to try to tell me how much time we had, describing the cancer to him as best I could. The family doctor, Dr. S_______ volunteered to come to my parents' home to try to talk to my father. He made a call on January 6, going no further than the bedroom door.

My father was angry, and told him that if he wanted to see him, he would go to his office. Dr. S______ was kind but firm. He was the last humane and courageous doctor we were to encounter. (p. ii)

February. On February 21st, on the strength of Form One (involuntary admission to a mental hospital) signed by attending physician, Dr. S______, the patient, William Bailey, was taken by the Edmonton City Police task force, to [Psychiatric] Hospital. Police were called because there were two rifles in the patient's bedroom, and, although he had never been a violent man, there was some fear that William would shoot himself when he realized he was 'in a corner'.

On February 22nd, William was released from [Psychiatric] Hospital on the condition that he go to the W. W. Cross Institute on Thursday, February 24th.

February 24th—William went to the Cancer Clinic. He did not go voluntarily again.

March. April 11 - Alice told Georgina that she was going to have their father picked up again. Georgina requested that Dr. B_______ be called on the chance that he might come out to the home and talk to the patient. Alice agreed reluctantly, feeling that William, knowing himself cornered again, might commit suicide.

April 12 - Dr. B_______ went to the Bailey residence, where he confronted the patient and told him he must go for treatment. William Bailey agreed to go Thursday, April 14th.

April 14 - Georgina went to pick up our father to take him to the Cancer Clinic. He said he needed an hour to bathe. She left. When she returned, he was gone. He had packed some food and belongings into his truck camper and left.

April 15 - Elizabeth (the patient's wife) appeared before a judge, who issued a warrant for the arrest of the patient, on the grounds that he was a 'danger to himself'.

April 17 - Elizabeth and Alice found William Bailey, in a campground one mile west of Spruce Grove. The Spruce Grove and Stony Plain detachments of the R.C.M.P. took him back to [Psychiatric] Hospital.

April 29 - After 12 days of treatment, the patient agreed to cobalt treatments.

May. On May 11 - William Bailey received his first and only cobalt treatment for the lip carcinoma.

May 22 - William Bailey died. (p. iii)

Excerpts from the Journal

Alice's journal up to October 22 (p. 9) provides information about her attempts to get her father to go for treatment for cancer of the lip which is, if treated early, one of the most curable forms of cancer. As noted in Alice's synopsis, her father not only refused treatment but cut himself off from his family. The trajectory of William Bailey's dying and the effect on Alice and other family members are traced chronologically.

October 22

> My dad was beginning to frighten me, because his belligerence, although it only manifested verbally, nonetheless indicated that he was sorely troubled, and, like a wounded grizzly bear, was unable to locate the source of that trouble. I didn't want to be in his range of vision if his vision momentarily cleared. (p. 9)

October 26

> This was the day for the second appointment, the one made the previous Thursday when that day's appointment had been cancelled. I phoned prior to going down. There was no answer. I rang the doorbell. No answer. I knew from my mom that Dad had been back in the bedroom, sleeping deeply since our session on Friday, and had suspected there would be no reaching him. I could have used the key to go into the house, but knew it was useless. Also, I was afraid. At that moment, I felt I had done all I could do. (p. 10)

November 12

For myself, this refusing to have his lip looked at, this refusing to be responsible for himself, was the first certain evidence that he was not himself, that he was slipping into a zone in which he was not able to make this decision about himself. I never thought he was unwilling to have his lip looked at - I believe he moved from a stage in which he was afraid to have his lip looked at to one in which he was unable to do so, and this, for my father, was unusual. In his good health, he was his own man. He knew what he wanted, and boded no interference with his decisions.

I didn't know it then, but I was never to see him again in a state in which I did not think him impaired, either from liquor or from his mental state. (p. 11)

November 12

Charlie [Alice's younger brother] had not talked to Dad since [an] incident over the truck and who should have handed him the keys. He had less patience than either my sister or I with the whole situation, and, to date, had nothing to do with any intervention, on the grounds that it was no concern of his. I phoned him and told him that Mom was out and Georgina and I were going to talk to Dad, and asked him if he would join us, suggesting that maybe all of us, his children, could move my father. He agreed to come along, but asked if I didn't think that maybe my father would think it was some kind of conspiracy, my mother being out. Recently my father had become more and more paranoid about my mother, partly because he didn't want her or anyone to see his lip, so he had to make sure that she was in the frontroom before he came out to pick up his food. Add to this a score or more of unresolved hurts over 42 years of marriage, and, when he was drinking, he lashed out at her, verbally, as if she was the source of all his troubles. She was helpless in the face of his accusations, and stricken by what he was saying. A reminder that he was talking through booze did nothing to ease her heart. It was difficult for her not to take these accusations personally, but I believe that, even then, my father was simply hurting, mainly from the cancerous growth, partly from an abcessed tooth in the same side of his mouth, and, like the injured grizzly, he lashed out in his pain and frustration at the nearest moving creature, most often my mother.

Until recently, he thought my mother was out to 'get him' and I was there to save him. (p. 12)

November 15

I was really troubled, and concerned about the negative kick I had given the situation by losing my temper, so wrote a letter (November 15th) which I took down to the house. Again, he was still isolated in his bedroom, so I used my key to get into the house and left the letter on the kitchen table, at his place, where he would see it, I hoped. (p. 15)

November 17

No word from Dad, so I wrote another letter, and went down again, in an effort to see him. This time, when I rang the doorbell, surprisingly, he came to the door. He was sober, but had that faraway look in his eye, like a wild horse that's been caught but not tamed, and who, even as it looks out at you, is actually looking in. Because we were able to talk, the letter I wrote it was not necessary to give him. We reconciled, declaring to one another that our love, our long association of father-daughter ties was too strong to be broken by one such event. (p. 15)

November 26

Dad has made no effort to go to the doctor, and his drinking was continuing, though he had slept deeply and heavily for almost a week after the last major upheaval (Nov. 12) except for the day he had opened the door to me. I bided my time, hoping he would, as he had said, go to the doctor. By the 26th, I was getting terribly anxious again, and wrote him a letter, taking it and leaving it at his place at the table. No response. (p. 15)

November 26

For days on end, there would be no sound out of the bedroom, and he would be in his deep sleep stage. Mom would know only by the empty plates that he was alive. Then, he would take to drink as the pain would come upon him, and, during those times, it was becoming increasingly difficult for Mom. Often, Dad chanted, wept, moaned, prayed to die - all through the night. My mother was working, and doing so many days on little or no sleep. He was so unusual, she began to fear for her safety. He would, when agitated, throw open her bedroom door and stand staring at her until she wakened, only to walk away when she did. (p. 15)

December

Our family remained split on alternatives re: action. I remained adamant that something had to be done, including having him taken forcibly to [Psychiatric] Hospital (the local mental hospital). My sister did not want to consider this alternative, and, when he (my father) asked for liquor, she would bring it to him. My mother was torn, having brought him liquor in the beginning, but no longer willing to do so, she was most anxious about any action in which we would take this psychic giant of a man, against his will, out of his room and into a hospital. My brother kept his distance, not taking any action of his own, but indicating he would support me in my decision, should I decide on force.

Sometimes, when he was drinking, my father would either throw food around the kitchen, or prepare it in such a state that it got thrown around. Always respectful of the possessions he and my mother had both worked for, he would never have dreamed of smashing things off tables, but was now doing so. It could be imagined that these acts were acts of pure frustration, simple relievings of the terrible pain he himself was suffering. Nonetheless, this was unusual behavior for him.

In this long dark month, my mother, time and again, came home, tired, from work. The sun would already have set, and she would come into a dark house, not knowing what she would find. Many times, she thought my father was already dead. Nonethless, she simply went about preparing supper, and, when it was prepared, she would knock at his bedroom door, tell him that his supper was ready, and then retreat to the frontroom so that, if he was able, he could get up and get it without her seeing him, as he had indicated he wanted to proceed. Some days he did not respond. If he did not drink that night, nor get up and take the newspaper into the bedroom during the night, she would not know in the morning if he was alive or not.

During this month, I went down to the house every

> second day or so, hoping he might be up during the day. Sometimes I would ring. If there was no answer, I would use my key and go in, hoping he might be up. I would sometimes go on into the bedroom, but he would be sleeping deeply, and generally unresponsive when I spoke his name. On about December 22, my mother phoned from work asking if I planned to go down that day. I had not intended to, but realized, from the desperation in her voice that she could not take one more time of walking into that house. She said she thought he might be dead - there hadn't been a stir for 24 hours, and no sounds. I was galvanized into action.
>
> Terrified, and knowing how Mom must feel going into that house every night, I used my key to let myself in the door. I couldn't stand the tension of going or not going. Going was the only alternative. All was very quiet. The house was already like a morgue. I knocked softly on his bedroom door, and when he didn't answer, I pushed open the door and went in. He was in one of his deep sleep phases, and his respirations and pulse were slowed way down, almost imperceptible. I didn't waken him, once I saw that he was breathing quietly and steadily. Relief flooded through me, that he was still alive. For his sake, and because of his suffering, I suppose I should have wished that he could have died, but I still couldn't believe that it was necessary, if only we could get treatment.
> (pp. 17,18)

Alice calls on her family doctor, Dr. S_______, to intervene with her father.

> January 6
>
> I met Dr. S_______ as planned, and we went into the house. I knocked at the bedroom door. No answer. I went in. Dr. S________ stood at the bedroom door and advanced no further. My father was sleeping with his head at the foot of the bed, so that he was about three feet away from Dr. S_______. The room was in almost total darkness, and he had the covers pulled up half over his face, so Dr. S________ could see nothing. The smell was overwhelming. (Dr. S_______ later told my mother he recognized the smell of cancer immediately upon entering the house.) My dad said "Who's that?" And I said "It's me, Alice, Dad, and I've brought Dr. S_______ with me." "Well that's a dirty, rotten trick," he said, in a strong and angry voice.

Dr. S_______ interceded and spoke quietly and firmly to my father, pointing out that the family were concerned about him, and rightly so, and asking him to see their point of view, and to have his lip looked at for their sake, if not for his, and not make them suffer any longer. My father told him that if he wanted to see him, he would make an appointment and come to his office. Dr. S_______ told him that this type of growth can be successfully treated almost every time, and it would be wise not to delay any longer. My father said, in a very loud and clear voice "I can't hear you Doctor." The total interchange took only abut three to five minutes. There was nothing more to do. We left.

I wrote him three more letters, only one of which he opened, and on which he wrote "Opened by mistake - return to sender - unread." The following two letters he never opened at all. I was later thankful for that because in one I told him to relax, that "no one is planning on picking you up against your will" . . . "take off your cowboy boots, don't worry about locking the door, and have a good rest, and then please get up and go for treatment". As it was, we did eventually pick him up against his will, and he would have held my moment of weakness against me as proof of the conspiracy against him. (pp. 18,19)

February

There was no response to my last two letters (January 22nd, and January 31st) and my mother told me they had not been opened. Along with other unopened mail, they lay on the writing desk. Dad never again paid any attention to any mail, except to sweep it all on the floor one night when he was drinking. (p. 20)

The first two weeks in February were a living hell for Mom. Dad was drinking more and more, and becoming more destructive and disorderly when drunk. He overturned anything that was in his way, swore excessively, (unusual for him) and now glared at my mother, not caring to cover his face, and looking 'wild' and frightening. She continued to try to prepare food for him which he could eat with a minimum of difficulty. More and more of his mouth was gone, with the bottom lip almost totally affected, and the black marks of cancer now reaching into his upper lip. It was bleeding frequently, and he didn't have it bandaged much of the time, being either drunk or sleeping off his drunkenness. He had a beard, and moustache, which partly hid the growth,

> but the hair of his beard now fell out where the skin was falling off his chin. My mother would find several spots in particular where he obviously, in her absence, stood and looked out the window, one window in the frontroom and one in her bedroom. Where he had been standing, there would be bloody stains on the floor. The cancer was weeping ceaselessly, and occasionally bleeding profusely. At one point later, my father told my sister that after it bled profusely he had some relief from the pain for awhile. Even as he was telling her this (it was when it was bleeding) he was unable to see how horrifying it was for him to watch this. (This occurred shortly after he was released from [Psychiatric] Hospital for the first time.)
>
> And so it was that my mother left their home on February 13, never to return, except in the presence of my sister and myself, to clean the house and prepare food for my father after he was released from [Psychiatric] Hospital, until after my father died. Later, she discovered my father had taken the little calendar which she kept near the telephone, a little upright calendar in which the days are marked by turning over a leaf, and he had scotch-taped the calendar at February 13th. It was obvious he felt betrayed and abandoned, and was totally incapable of seeing, from another person's perspective that it would be impossible to live in that situation, watching him die like an injured animal.
>
> Early that week I arranged an appointment with Dr. S_______ and my mother, my sister and myself went in to see him. My sister, now very quiet, agreed with me that forced hospitalization was the only alternative left to us. (p. 21)

The next few pages report on Alice's experiences with the medical system trying to get help for her father who was deteriorating physically and emotionally. Finally, the family had Mr. Bailey forcibly taken to the [Psychiatric] Hospital. Alice's report continues:

> February 21
>
> It was during this time that, had he been kept in hospital, I feel his life might have been saved. (p. 23)

None of us could have imagined that in less than twenty-four hours, my dad would be released from hospital, considered to be capable of looking after himself, and back at home, furious, injured, and still very, very sick. His paranoia now knew no bounds. His drinking increased, and, while he did keep his promise and go to the Cancer Clinic for diagnosis, he never went back for treatment, as we knew he would not. It was the beginning of the end. (p. 24)

And so it was that my father was released from [Psychiatric] Hospital on February 22nd, obviously ill from a carcinoma of the lip which by now had grown so large that he kept his entire mouth hidden when he talked. So much of his bottom lip had been eaten away that it was difficult to make out his words, and he had to put extra effort into forming the words when he spoke. He had lost one-quarter of his body weight. His eyes were becoming sunken and he almost constantly had the haunted look of a paranoic. (p. 29)

April

Six weeks had passed, and I was determined to take action again. (p. 29)

I phoned Dr. B_______, to tell him that Dad had not returned for treatment, although he had gone for diagnosis, that the situation had decidedly worsened, and that we were going to initiate action again. He now had some suggestions to make, and suggested we do as follows:

Steps:
- Try taking him by family assault (so he won't sue the doctor)
- Then, he must be free to walk away from the hospital.
- Don't argue with him - convince him non-verbally by the action of taking him. Take him as if he is a child - be firm and insistent.
- When you get him there, he may elect to stay (see Dr. O______ about which hospital to take him to) (It would be good if he did not drink before then) (!)
- If this doesn't produce good results, phone Dr. B_______, and the social worker will go and see Dad. Then Dr. B_______ will go and see Dad. Then maybe we get an order for apprehension from a magistrate swearing that our father is suffering

> from a mental illness which now makes him a danger to himself.
>
> I think, on second thought, that my sister phoned Dr. B________ and got this information. At any rate, it was at this point that I began to keep a note-pad by the telephone and jot down conversations. Information from this point on is taken from these notes.
>
> When I had told my sister that I planned to have my Dad picked up again, she begged me to permit her to ask Dr. B_________ to intervene by visiting Dad at home. I was opposed to this, on the grounds that a warning would trigger off a suicide, and told her so. Nonetheless, she was so distressed at our having to do this to Dad again, that I listened to her and agreed.
>
> April 7
>
> Georgina and I went together for the "family assault". Dad responded nicely to Georgina and asked who is here? as if he knew she wasn't alone. He was still lying in his darkened bedroom. The smell was almost unbearable. He was moaning incessantly. When Georgina said "It's me and Alice, Dad" he became angry and said "I told you I didn't want to see Alice!" She talked to him and I stayed back out of it. He insisted to her that he have his guns back. They had been confiscated by the police on Feb. 21st, and turned over to Charlie. He had asked for them time and again since then, and Georgina had only ever tried to re-direct the conversation when he began to ask for them. I heard him begging her for the guns. She tried to make a deal - that he could have the guns if he would go back for treatment. He said he wouldn't make a deal.
>
> I went in to try to talk to him, but he just rejected me. In spite of that, I put my arms around him and hugged and patted him. He just moaned and moaned. I tried to talk to him, to tell him we loved him, to plead with him to come for treatment but he kept up his chanting moan to block out the sound of my voice. I said "I love you, and I know you love me, no matter what" at which point he cried. It was so pitiful. I couldn't stand to see him so. (p. 30)

The family tries again to get Mr. Bailey in for treatment:

April 14

In late morning, April 14th, my sister went to pick up my father for his appointment at the Cancer Clinic, which had been arranged hastily the previous day. When she got there, he was sleeping deeply, and, when she awakened him, he asked for an hour "to bathe and prepare himself" for his appointment. This by the man who had not bathed for almost nine months.

She left, and when she returned, my sister found that my father had somehow packed some things into his camper truck and left, sick as he was. Distraught, she phoned me, confessing that, looking back on it, he had given indications that he would suicide. He had left a note telling her 'not to worry', that he had gone to 'see a fellow he might never see again'.

I phoned my mother at work, and we went to the house. By now it was about 2:00 p.m. There was evidence that my father had taken a cooler, some food, sleeping bags, and, his truck was always equipped for camping if necessary, so he was supplied with the basics. Whether he had the strength to look after himself, or how he would buy food, was another question. However, at that moment, none of that crossed our minds. In my own panic, I was personally convinced that my dad would drive out west (this was before I realized he was well-outfitted for a few days) and turn the ignition on in the truck and end it all immediately. It was now more of an emergency situation than ever. (p. 33)

April 16

Everything was blurring into a terrible fog of sleeplessness. I felt we were all dying of my father's illness. If my father had been at the house that night, I don't think I would have had any energy left to do anything other than stare at him. I was getting close to being totally useless. (p. 35)

There was an R.C.M.P. office in Spruce Grove, and an efficient and compassionate policewoman named Seargent K_______ who grasped the situation in an instant. By this I mean that she grasped the situation as it was, as it was for us, the family, and as it was for my father. She got on to the phone and contacted the R.C.M.P. at Stony Plain, arranging for the town doctor to assist in case my father had to be sedated. "This man is older, and very sick," I heard her say - "He's proud and will resist being picked up. We don't want him to hurt himself if there has to be a struggle." It was almost more concern than we could bear. We will always be grateful to her, and how she handled the next painful hour. (p. 35)

Almost anyone involved with the situation couldn't believe it could be happening. (p. 36)

May 6

Unable to stand it, I left the room, only to see Dr. B_______ coming out of his office, which was across the hall. "He's going to die, isn't he?" I said to him. I knew, with certainty, that he was beyond treatment. (p. 42)

May 7

On Saturday night, Dad was all cleaned up. Mom and I went in together. He didn't motion us out, as he had done previously, but when I took his hand, he pulled it away. He just stared straight ahead. Once again, it seemed he did not realize we were there, but we couldn't tell for sure. (p. 42)

May 9 (evening)

Mom and I went to see Dad. He was transferred there for the last blood transfusion. He was still disoriented. I was alone with him for awhile. I sat beside his bed, touching his arm and hand, ready to draw away if that annoyed him. At first he simply stared off into some inner distance, unseeing in this world. Then he spoke to me, saying my name in the soft lovely way he had of saying it, and stroked my hand with his hand. With his forefinger and his middle finger, he brushed the back of my hand, imparting the only message of love I was to receive in those final days. His hand brushed my hand, and his voice brushed my heart, and I can feel that touch today, and never without an unbearable yearning and longing for him. (p. 43)

May 10 (evening)

We were together but locked in our own worries that night. It seemed possible that Dad would not have the strength to survive the [proposed] surgery.

There we were together, but grimly alone. We were aware of the compassion of the staff members, but we were also aware that caring for Dad, the smell of the cancer, made this one of the most difficult tasks for nurses and orderlies.

How much more suffering and pain could he bear? (p. 44)

Friday, May 20

Mom talked to Dr. M_______ and he said for her not to wear herself out coming to the hospital - Dad didn't benefit by it because he was not aware, and she was just tearing herself up.

I couldn't stand any more. I went into the room, but Dad was stuperous - his eyes half opened, looking where I didn't know, not out, not in. His mouth was open, and he struggled for breath, his saliva rattling in his throat. I saw his tongue, half-eaten by the cancer. How much longer could he last? Dr. S_________ had said that, without treatment, he wouldn't see the end of the year. It was now almost the end of May. If he didn't get better, was he going to suffer like this for seven more months?

We were at the point where we couldn't bear to see him, and we couldn't bear to stay away. (p. 49)

Saturday, May 21

Mom phoned the hospital and talked to the attendant. Dad's blood pressure and temperature were fluctuating - up and down. His condition was still very poor. Dr. M________ had said that if lifesaving measures were discontinued, he wouldn't last two days.

Dad's hemoglobin was dropping - he would need more blood soon. The attendant G________ (whom Dad had seemed to like) said that on Friday night Dad had bit down on the suction tube, so that it wouldn't work, kicked at the staff, and tried to pull out the intravenous.

Sunday, May 22 (afternoon)

I phoned. The nurse in charge said that Dad had been taken to an acute care hospital the previous day, and an intravenous attachment had been inserted, permanently, into a deep vein in his leg. Now there was no need to constantly re-insert the needle.

Morphine was finally ordered today and he had his first shot. It gave him, said the nurse, some real peace.

We know that morphine is a terminal decision. I phoned his two sisters, to prepare them.

Sunday, May 22 (evening)

Dr. T_______ phoned at 6:40 p.m. to say that Dad had died between 6:00 and 6:30 p.m. He was pronounced dead at 6:30. He had died peacefully, considering. G_______, his favorite attendant, was with him.

At about 6:00, Dad was found to have no pupillary response to light (his pupils dilated, and would not contract); no pulse could be found. His breathing was intermittent. Only a mild attempt (gentle heart massage) was made at rescucitation. One by one, the doctor said, his vital systems slowed down, and stopped. (p. 49)

Sunday, May 22 (8:30 p.m.)

Mom, Georgina, Charlie and I went out to the hospital. We talked to Dr. T_______ and G_______ and then went to see Dad one last time.

He was in the hospital morgue, wrapped in a shroud, only his head exposed. His ears were white on the top half, red on the bottom. I touched the bottom half to see if it was warm. It wasn't. His forehead was cool. For the first time in almost a year there was no suffering written on his face.

He was gone.

June 1

Conversation with Dr. M_______:

Cause of death (major): Massive fungating carcinoma of mouth and throat.

Cause of death (contributory): general asthenia (weakened physical condition).

He was opposed to a post-mortem. "There's no way you can locate the source of a death wish."

> Dr. M_______ said this was the worst case of cancer he had seen, ever. (He himself was white-haired and in his early sixties).
>
> He said the people at the Cancer Clinic felt the same way.
>
> His own great-uncle had died of cancer of the face when the doctor was a boy. There was that same smell. He said he would never forget it, and recognized it immediately when he saw Dad.
>
> He said of Dad:
>
> "Freed at last."
>
> "He did it his way."
>
> "He took his reasons with him." (p. 50)
>
> My father has turned to earth,
> My father, whom I love, has turned to earth.
> Shall I not also have to lie down, never again to
>   rise?
> How could not then my cheeks be hollow, or my
>   countenance bent,
> How could not my heart be sad?
> How could I not resemble a wanderer of distant paths?
> How could I be silent? How can I shout it out?
> My father, whom I love, has turned to earth.
> Since he is gone, I find my life no more.
> (adapted from a Sumerian epic)
> (Preface to the Journal)

Three letters written by Alice to her father are included as Appendix 9. The letters show something of the desperation that Alice felt and her attempts to communicate with her father.

October 19, 1986

I called Alice mostly to again receive permission to "use her very personal experience as data." "Yes, I could," she said. Then Alice talked about how it is with the family now.

No one talks about 'it,' but 'it' is still there lying unresolved amongst the family members. 'It' is the dying of her father. Her mother Elizabeth has had cancer of the colon which was treated in time and she is doing well. Sometimes Elizabeth calls on the anniversary of William's death or birthday and they talk around it. Georgina, Charlie and Alice don't discuss it.

Whether or not Alice's experience is a matter of concern for health care professionals is in the domain of personal values. I personally believe with Alice that "suffering is an opportunity for growth" (Dabrowskian philosophy). However, I alsc believe that health care professionals ought to do everything in our power to alleviate suffering. "Cure sometimes but comfort always" as it has been said is the professional's mandate.

It becomes apparent to me that the family caregiving experience is so entwined with the patient's dying experience that to study one without the other is an impossible task. It seems necessary to try to understand the patient's perspective on the dying experience in order to help families cope with caregiving to those patients who are beyond cure.

Nan, Joe's wife, had said to me during one of my visits, "Do you want to know what it's like to die? I'll tell you what it's like." Nan offered to write some notes for me and she gave them to me at my next visit with Joe and with her.

The following items are transcribed as she wrote them with the only changes being that of names where confidentiality is necessary.

Nan's Notes: The Patient's Story

I'm sick, not stupid.

What I expected in Feb - to be protected in cotton wool
- a world of love and tenderness to compensate for the ugly reality.

What I know now - I'm alone - my problem not the only one. Living can be just as hard as dying.

What I expect now - to learn to not be bitter or expect too much
- to depend on myself first, others second.

What is the Reality - I'm going to die, the best way I know how. Fear of dying does not bother me, the pain of dying terrifies me.

My choices for my death

1. Hospice in States or Britain

   Have written to friends in Tacoma to look into this.
   Have cousin in Britain who is a Matron - have not written to her for information because her mother is in last stages of cancer.
   Have contacted Alberta Health Care and Confederation Life.
   Not much hope of being covered outside of Canada.

   Why - Comfortable death - easier on me and my family not to see me suffering.

   Drawbacks - money - lack of family and friends.

2. Palliative Care Unit

Edna M is checking into this.
Dr. K_______ says she will try to get on list.
Joanne will talk to Dr. K_______ also.
Have to find out if Dr. T_______ can help.

Why - to get best care possible - relief for me and family.

3. At Home

Insurance covers private nurses.
Dr. K_______ says Palliative Care has mobile unit.
Have hospital bed.
Have a homemaker and have met health nurse.
Will my doctor make housecalls?
Friends willing to help.
Joanne will come home for that time period.

Why - stay in familiar surroundings - might be easier for Joe not to rush to visit.
- medication stronger at home by prescription than in hospital.

Drawbacks - may not have trained personnel close by when something happens.
- not enough support people - too much tension between Joe and family and people helping.
- Joe will work too hard.

4. [Local] Hospital

All personal experiences at hospital are very favorable but have heard dying patients are ignored - medication is stronger at home.

Sick - not stupid
- not deaf
- not 5 years old
- not contagious
- not gone to the bottom of pecking order
- not an object of pity
- not a subject of conversation

Sick and - afraid
- uninformed
- hurt mentally
- expecting others to:
understand
to help
to love
to hope
to believe

Hate thought that everyone's talking and feeling sorry for us. Am very private person - don't like people knowing my business - this really offends me - no one will honour my wishes in this.

Should have Social Services person with you from first onset of serious problems - no one knows how to cope, react, how to act - what's normal behavior - to draw family together.

Against staying home

- too hard on Joe
- not enough trained help
- friends willing to help - not knowing how
  - too embarrassed to let them.
- embarrassment for family too.
- family fighting and uptight.

The Patient's Experience Told to the Family Caregiver

During the visit with Joe that followed Nan's offer to write about her experience, Nan joined us to talk further about her feelings and thoughts about dying.

The transcript of the three way conversation with Joe and Nan is included for two purposes. The transcript demonstrates the differences in data collected by paper and pencil (Nan's Notes) and data collected in the process of conversation. The inclusion of the transcript gives more concrete evidence of the way the family caregiver, the patient and the researcher worked at understanding the experience of dying at home.

The following transcript is (1:4:1-20)

Joe and Nan

R You were saying about early on, your needs. Just—

Joe Somebody to lead you through. To—

R Um hum.

Joe To tell you what you're supposed to do. Where you're supposed to go.

Nan How you're supposed to feel. How you're supposed to react.

Joe What's available. What, what services are available to you.

R You were saying that you found that out just really by chance.

Joe Yeah. You find out most of it by accident. You just kind of stumble across things and as I say, even the help that's available at home. Half the time you don't know where, you know, where you're supposed to go in the Cancer Clinic or who you're supposed to see. [Pause] I don't know.

Nan It's a matter of—

Joe Even the—sorry—once we got the service, you know, the home care service, to find out that there were other services available, you know, other things that Nan needed that were available. Again, we just—you find out sort of by accident, by stumbling across things and—[pause] (Lack of information)

R Can you tell me about some of the needs that you found for yourselves?

Joe Well I guess the biggest one was home care, someone to look after the house and—

Nan Homemaker service.

Joe Homemaker service and [pause] the things that are available from the—I don't know—the bed and the—

Nan That's from SHU.

Joe Well yeah, but they're from—

Nan Aids for . . . Living

Joe Yeah.

R So equipment.

Joe I wouldn't even know the place existed, at least I didn't.

R Um hum.

Joe And what a wonderful feeling when Laurie came in and she said, okay, what can I do for you? What do you want? If I'd asked for the moon, Laurie said well it'll take me a couple of weeks to get it. But other than that, um, the bed we got—we had looked into buying a bed for ourselves and they're very, very expensive. (Support matrix: What is available)

Nan Only going to do it [dying] once. Got to get it right the first time.

R Um hum.

Nan And ah, people like you to talk to. [Pause] That's important. As I say, I think the social worker, someone trained in dealing with people under crisis should meet you at the front door and stay with you. Is that—

Joe Um hum.

Nan Is that right?

Joe Well, until you get yourself sorted out.

Nan Yeah.

Joe Find out what's going on. Yeah.

Nan It's—

Joe And then they should be available when questions and needs arise eh. That's right. (Expectations of the health care system)

R So in a sense, if you had had someone, your caseworker, your social worker, someone you could get in touch with at any time, just to ask questions or—?

Joe Um hum.

R For clarification or that kind of a thing, that would have been a helpful thing?

Joe Um hum.

Nan And someone who would feel free to come in and be part of our family, like you're doing and so you're not just a number, you're not just a five letter number that's punched into a computer and—

R So really, somebody earlier.

Nan Yes. Because I think the earlier you start to handle, it's like any other drastic change it your life. The earlier you start to handle it, the better it is.

And therefore you progress up instead of deteriorating into a panic or whatever you want to call it.

I found that Joe went away for a week and I am very able to take care of myself but there were—things came up and I didn't want to phone anyone for help. I didn't want to ask for help. If I couldn't have Joe help me, I wasn't going to have the help at all. And that is not fair. It's not fair to Joe.

Joe I feel a little better than I have. A lot of the pressure has been taken off, or some of the pressure anyway. [Sigh] I comes and goes.

Quite frankly I find it's time consuming [trying to get help or go for counselling].

I've got more important things to do with my time than go and sit and, you know, spend a half a day driving over there [to counselling] and then sitting for whatever length of time and half the day driving home.

Because the problems that I have require, you know, require action. They required something to be done so—

Nan All the time we were in the office, in the counsellor's office, I kind of feel that you're kind of chomping at the bit to get out of there.

Joe That's right. Squirming to get out, to get going and do the other things that I have to do.

It goes back again to starting earlier I think. Because basically by the time we got to talking to [a counsellor] or anytbody we'd been on our own for almost two years. A year and a half and you have already coped with most of the problems that have arisen. Or not coped. Whatever. But by that time they're in whatever state they were going to be in and there's not much that anybody can do to change them. (Coping strategies)

Right?

Nan Right. The damage has been done or it's been cleared up.

Joe It would have helped a lot earlier.

Nan Yeah. Last February was when we desperately needed help.

Because I—

Joe Well even before that.

[We needed] explanations as to what's going on, of what you can expect. (Need for information)

You know.

R Would that have scared you? Or helped you?

Joe Probably not. Not as much as not knowing.

Nan Yeah.

R So explanation about—where to go even?

Joe Um hum. And [pause]]

Nan I think it's somewhere in those notes. [Nan refers to her notes that she wrote for me about dying.] When we first—

Started this whole thing. Okay. Last February I started out with this notice coming in, they wanted to do more tests. My back was sore. I put two and two together and I panicked right then. And I was useless. And at that point in time all I wanted to do was someone to wrap me in cotton batting and protect me. I couldn't cope with anything at all. You know, looking back. It's nice to look back. You can see these things. And there was nothing. I mean it wasn't even sure that it was, it had spread. There was nothing sure except I knew it was.

Because all I got was a piece of paper in the mail. I talked to doctors. They said nothing. Okay? And that's what I expected. [Pause]

A very cold situation. A very scary situation and I just felt like a trapped animal. Whereas if someone had sat down and said, now look, we've got some bad news and this is what it might be and it could be this and we'll do this and that could happen and just sit down and make you a person instead of just this quivering mass of—[pause]

R So you need information?

Nan Umm.

Joe Umm.

R And you need to be able to express yourself?

Nan Yeah.

R And are there any other specifics? [Pause]

Nan My whole family thought—when the kids found out I was feeling sorry for myself—and I just now thought of it, but you know when you're that far gone you can't snap out of it. It's beyond your control and [pause] there was no one there to tell us that.

R Would it have helped if there could have been someone to explain to your family what you—

Nan Um hum.

Joe Well anybody that could let them know what was happening. I guess basically I didn't say anything because I didn't have enough information myself. Particularly my son was left in the dark. He just had no idea of what was happening, what was going on. And—as a matter of fact, I think he found out from Joanne. It's just—you know it's not anybody's—that was trying to keep a secret or was any, you know, big secret. It was just that nobody knew what was going on. Everybody was kind of putting pieces together and trying to figure out on their own what was happening. (Lack of information)

Nan And I wasn't being a good mother. I wasn't being a good anything. I was just . . . at that point in time.

Joe Yeah. It wouldn't have taken much. It would have taken, you know—

Nan Instead of the weeks of hell that we went through.

Joe Yeah. Just, you know, an hour of somebody's time to explain what was going on and what was, you know, what was coming. Again, you just kind of stumble from one place to another and— (Expectation of professionals)

R What was coming in the way of how [pause]—

Joe Well treatment and, you know, what Nan was going to be feeling like.

R Um hum.

Joe Another thing that we just sort of stumbled on was, you know, the drugs that she uses. What side effects, what they do to her. What—

Nan [The counsellor] got us a book out for that.

Joe We had no idea, you know. I was getting ready to shoot her just because she was being so obnoxious.

Nan I've never been obnoxious in my life [laughs].

Yeah, well this is just it. How does one person know how to cope with another when the reaction—when they're actually taking—

Joe When you don't know what's causing it.

R Um hum.

Nan It's like I said, I'm angry and I'm angry because I have cancer. But that's not how my anger comes out. My anger comes out because H_______ said something about my hair and Joanne banged up the car or, you know, or this type of thing or didn't put a coat down properly.

R Um hum. You're looking for a place to get rid of it but it's often times not getting right at the—

Joe Um hum.

Nan Right. A cat to kick.

And other people have to know, heh, she's not angry with me. She's angry because of—it's like Joe will say, are you hurting? And how can I tell him how much I'm hurting? What is a—

Joe Yeah. What's pain?

Nan A criterion for it. How can I describe it to him?

R Um hum.

Nan You know, it's a joke around here. I'll stand up and do something and all of a sudden I've got to sit down. And I make a joke of it. But I'm hurting and I have to sit down right now. But to try and do it without making everyone feel sorry for me or making everyone upset. It's no big deal, it's just I have to sit down because I'm hurting and how do I tell you how I feel? It's like the old saying. Where did you go? Out. What did you do? Nothing. (Coping strategy)

R How do you pick up the cues?

Joe I don't know.

Nan The bitchier I get, the more I'm hurting. [Laughs] I mean there's this to it. And that's too bad. The bitchier I get, the more I need help and the more I try not to have it.

R What I'm imaging here is that it would be helpful to have an interpreter in a way.

Joe Oh yeah.

R Rather than a counsellor?

Nan No.

R As well as a counsellor?

Joe Well I don't know.

R [Pause] I just keep wondering how does a person help a self-sufficient, independent—

Nan Stubborn.

Joe I'm probably a very poor person to ask that. I don't know. [Laughter] I—yeah. I don't like to ask for help.

R Yes. So how do we pick up the cues?

Joe I don't know. How do you pick up the cues? Frustration level I suppose.

R Um hum. [Pause]

Joe It's like everything else. Most of the problems go back to communication.

R Um hum. [Pause] Do you sit down much like this and talk?

Joe No.

Nan You're too busy.

Joe Never. Ahh. I shouldn't say we never do, because we do sit and talk but not like this particularly but generally in the afternoon we'll sit and talk about what's going on or what has to be done.

R And how you're feeling?

Joe Not very often.

Nan No, not on a personal plane. Get him onto politics and he goes like a dingbat.

Joe Who?

Nan You. [Pause]

Joe and Nan go on to talk about 'red tape' and the things that irritate them.

Joe A lot of it has to do with the running around to get things going, isn't it. Umm?

Nan Yeah.

R Do you need a coordinator?

Joe Probably. Yeah. That's I suppose one way of putting it. But even, you know, you find out about things that are available but to get them going you have to take the time to go here and go there and talk to this person and see that person. (Support matrix) (Expectation of health care system)

R Um hum.

Joe And it gets very time consuming.

R Um hum. So if that person could come in and you could express your needs and concerns?

Joe Um hum.

R They would have a knowledge of what's available, who to call—?

Joe And what can be done and—yeah.

Yeah. Which person to call, you know. It's surprising you phone, and they say oh you have to phone so and so for that because I handle something else and then we say well, okay, how do I get ahold of them. You know.

R Too many specialists?

Joe No, I don't know if it's too many specialists. It's just that you end up not—and again, not contacting the right person, umm, how do you say that [pause]. Even with ________ when she was here, she would say, well, you know, you can get such and such through so and so and I would phone them and they would say, well no, you have to go to this one and so you'd say well, okay, how do I get a hold of that one.

Nan It was like my days with the memorial society.

Joe Umm?

Nan Well trying to get the memorial society.

Joe Oh. Trying to find them.

Nan Three different phone numbers.

It takes a lot of patience, you know, to get the information that you really, really want.

R Um hum. And persistence?

Nan Yes. It sure does.

Joe It's like this memorial thing which I didn't even really realize that it was an ongoing battle trying to get a hold of them. I had no idea that you were— (Lack of communication)

Nan Well I didn't want to bother you with it. I figured that was one thing that I could do for you.

R Um hum. [Pause]

Nan And I would have got a hold of them. [Pause]

Joe Get me to look.

Nan Yes. But as I say I've got cheesed off for a week or two and then I got back to it. And it's like, well all the things that I've been doing have been done [pause] to get where I want to go and I'm trying to leave as many options as possible open. (Lack of information)

Joe continues to talk about stress, the need to do many things, to worry about not only the present but to think about the future.

Joe Um hum. Oh sure. Very much so. It's not a very pleasant place to be after you've worked thirty years and look after your future and find that there's nothing there anyway so— but [pause] it's not something that you spend a lot of time worrying about. As I say I have a few years to start over and I have my health and I have a job so it's just a matter of starting over.

R Um hum.

Joe But, yeah, you worry about it. [Pause] As I say, you worry about your pension plan and whether that's going to be adequate and whether that will exist at all.

R You're thinking long range?

Joe Long range, fairly long range.

R And Nan was saying you're thinking every day is going to be good. We have to make every day good.

Nan Yeah. [Pause]

R Does it help to talk about it, to understand the other person's perspective on it or—

Joe Probably. I don't know.

Nan Oh yes. Yeah. And actually if I know that he has some goals for the future it makes me feel better because then I'm not leaving him, you know, up the creek without anything to live for.

Joe Umm. [Pause]

Nan Right?

Joe Right. [Pause] But this—the economic situation has created all kinds of other problems, like I had felt because Nan's time is limited, we should be doing things. There's things that should be done and this is stopped anything that we are planning to do or able to do. Now it just—we have to just wait and right now is a bad time for Nan to be marking time because there isn't, you know, her time is limited so it's a—it puts another added pressure.

R Um hum.

Joe If you want. It's something that's in the back of your mind all the time so— [Pause]

Nan Well I feel better after today.

Joe Um? Sorry, you feel better after today?

Nan Um hum.

Joe Why?

Nan Because—well, you know what's been really worrying me? How I'm going to die.

Joe Umm.

Nan And I think I know now.

Joe How did you find out? Who told you?

Nan Well, all my options are written down there [Nan refers to her notes on dying] and if I can get my name on the Palliative Care list and if that can come about, and I can stay home as long as it's necessary. They will come to me, I know that. I talked that over with my doctor. I can be comfortable there for not as much of a drain on everyone.

R It's what you needed to hear?

Nan Um hum.

We should have stopped talking here. We continued to talk, to analyze. Joe talked about his stress. Nan became quieter and obviously bothered. Three things are noticeable that are instructive to the researcher:

One: In talking to both the family caregiver and the patient, there is some difficulty in keeping the appropriate balance of attention to each person's need to be heard. As Nan said, "It's almost like I want my day in court."

Two: Joe, as he frequently did when feeling concerned, came on strong with tough words. Joe would draw back and then continue to talk in tough "brave" language.

Three: Tearfulness frequently accompanied "feeling better," feeling "understood," "letting go" an aftermath to the stress rather than happening during a stressful time.

R	Nan did we ignore something there? We kept on talking and I just wondered—
Nan	[Pause] No. Keep on talking. [Pause] I think maybe I was trying to get through what my concern was and how I feel better about my concern. [Pause] That's all. [Tearful]
Joe	Umm. [Pause] So I'm not going to have to take a gun out and shoot you, eh?
Nan	Well maybe, we'll see.
Joe	Oh, okay.
R	You've . . . [tape off]

The tape gets changed later and the conversation continues:

Joe	Well we've even looked at—like I have, I should maybe give it to Edna, that stuff that came from Mexico. We actually wrote to, what's his name, Dr. —
Nan	C_______.
R	Laetrile?
Joe	On the laetrile treatment and unfortunately I am from Missouri and I don't believe all this garbage.
R	Um hum.
Joe	That they've . . . and they start talking about six or eight or ten thousand dollars

for treatment that doesn't have a guaranteed success rate. But certainly if you can't get proper treatment in your own country then you go where you can regardless of whether insurance covers it or anything else. I can rob a bank the same as anybody else can.

R The one thing—

Joe And I've got the guns to do it! [Laughs]

Nan These are alternatives that you have to have worked out now, you can't wait until it's too late.

R Um hum.

Nan And this is where some of my terror is coming in. I don't want to leave everything until I am at the threshold where I can't function.

R Um hum.

Nan Then it's too late to do anything with me or for me. So whatever has got to be done has got to be done—

Joe Everything has to be preplanned and it's—

Nan This is what I'm trying to do. I asked you the other day, remember I said, do you really want to help me? There were some things you could do.

Joe Um hum. I don't remember what they all were.

Nan Because I'm not being paranoid about it— it's just that I want to—by the time I really need it, it's going to be too late to start anything.

R To start the planning.

Nan Um hum. This is why getting my name on the list is important.

R Um hum.

Nan And [pause] I mean I don't want to go—move into St. Christopher's in England, but they do have a better system there as far as pain control. But if I can get it here, that's great.

R So much the better.

Nan Um hum. Like we have friends in Tacoma and I've written to her and asked her to look into the hospice situation there and prices and what their laws are on drugs. And she will write me back on it.

R So your priorities really are pain free—

Nan Um hum.

R And then some of these other things like dignity, well I guess they're associated, you can't really parcel them out that way, but—

Nan Being in control of me.

R Being in control.

Nan Yes. I have this fear of being a thing that anyone can do anything they want with because I haven't got a mind or I haven't got a will to think for myself.

R And—

Joe . . .

R But is that what you mean about kind of talking things out before hand?

Nan Yes.

R So that you know what everybody—Joe at least knows what your wishes are?

Nan Yes. [Lists things for Joe to do.] Talk to Dr. K_______ about the palliative care. Make sure she did put my name on the list.

R Back up is what you're asking?

Nan Um hum. Somebody to go to bat with me.

R Um hum.

Nan Get a hold of Dr. T______ [an informal contact]. I don't know if he has any—

Joe He's a heart specialist. He's—

Nan At the General.

Joe Umm? He's at the University Hospital. (Support matrix)

Nan Okay. So if I'm on the list we can— There were a couple of other things.

Nan talks about wanting to go to see the Palliative Care Unit—with Joe, if he's "not too busy." Plans are made to link Nan and Joe with personnel at the Unit to set up a time for the visit.

We all feel more relaxed. Perhaps Nan's fears have not been adequately heard yet—a beginning only. I memo: "I must learn to keep quiet . . . not interview . . . less analysis."

Nan continues:

Nan Um hum. I mean when you come to the realization that you're going to die and that's hard enough to come to and I've passed that now, that's okay. I can live with that. No pun meant. And then you reach the stage where it's how we die that's important. And I'm sorry, it's my life and this is what I'm interested in. So. And how the whole thing is going to affect my family. So it's not a bad experience. Edna agrees with me that when the obituary goes in the paper I'm going to put don't send flowers, bring booze. [Laughter]

R I think that would be a real touch of class. [Laughter] I hadn't meant to stay so long today.

Nan Have a good old Irish wake.

R What about these notes? May I copy them or do you want to keep them?

Nan I was going to keep on adding to them.

Yeah. And the need for someone who will come to you instead of you having to—

R Go chasing?

Nan Yes. You get very discouraged and I think that you're so emotionally low anyway that your discouragement is twice as evident as it usually is.

The Other Kingdom

There is a CBC documentary called "The Other Kingdom" that got at this phenomenon of the other world of the patient. The documentary clearly showed the closeness, even intimacy felt amongst dying patients that they were not able, for the most part, to feel and communicate to family, friends or professionals. I had watched the documentary by chance while in Edson doing a workshop for home care nurses. Some of the other home care nurses had seen the film as well and agreed that there was a phenomenon here that they had observed too.

Nan had tried to explain the phenomenon of what keeps the "victims" of cancer in particular, feeling separate from those who are well. The separateness perhaps leads to a feeling of community with others who are dying from the disease.

Nan talks about the lack of dignity the person with cancer feels. Joe and their daughter Marg try to understand the experience in the following conversation that was also transcribed. Joe starts:

Joe [During treatment and examination] people are poking and prodding and—

Nan There's no dignity left at all. And I object to that very much.

Joe Actually, it would be better done with a screen.

Nan Yeah.

Joe So, you know, your privacy is—

R Is it as bad when it's just you and the doctor?

Nan No.

R Like you don't sort of feel that same lack of dignity but if there's someone else, even Joe—

Nan Yeah.

R As close as he is to you.

Joe A third person I think always does that. It's a fact of life.

Nan Yeah.

Joe That—

Nan And the fact that, you know, you kind of want your husband to see you in your best side. Not your worst. And I think the closer you are to a person the more you're prone to feel a degradation. Which is another thing that kind of bothers me about what we're going to go through.

Joe What? The degradation? You feel that this is going to be—

Nan Yeah. And I have the feeling that cancer is kind of a degrading thing.

Joe Hog wash!

R Can you say some more?

Nan Umm. What it's done to my body already. I'm disfigured. What it's doing inside to my body. It's like a [pause]

Joe Like a cancer.

Nan Eating away at my insides.

R Um hum. Um hum.

Nan Yeah. It's—it's not civilized is it?

R Doesn't fight fair.

Nan Yeah. That's a nice way of putting it. [Pause] Um, there's something acceptable about saying you have a heart condition. People can take that. But you say you have cancer—yick.

Joe That's a North American—

Marg Why?

Joe That's a North American problem. That's one of the—

R . . . deal with it.

Nan You feel . . . [talking together]

Joe Sure . . .

Nan That's my feeling. Umm, this thing is—

Marg People are more—

Nan I mean, a heart—

Marg Afraid of cancer.

Nan Yeah.

Marg But not with . . . there is not—

Nan But it—

Joe But it is Marg. People are afraid to touch you, to be near you, to kiss. You know, a lot of people don't understand. (The stigma of cancer)

Joe Yeah.

Marg . . .

Joe If you listen to people that talk about cancer—it is a North American problem. This is one of the things that we have a hangup with that it is an unclean disease.

Nan Yeah.

Joe You feel like a leper?

Nan Yeah.

Marg Really?

R And pain is such a debilitating—

Nan Demoralizing.

R Demoralizing more than debilitating. (Pain is demoralizing)

Nan Um hum. This is one thing I said to Dr. B_______—that without the pain—I'm not taking pain killers and I feel more like a person. And she didn't go to the fact that because you're off the drugs, she went to the fact that because you're not in pain, that you're feeling more like a real person. And that's true.

Joe Yeah.

Nan It's like . . . people who go into mental hospitals. You find them after a few years, they don't have the empathy, the sympathy towards their patients. It wears off. And this is the same feeling that comes through.

And I spent so much time at [the hospital] and bumped into a good friend there—he went on the little white pills I was on. Peter's dead. Four months later he was dead and why talk to him? Bruce, the person who was sitting beside me, said that I made that person feel better because I'm a cheerful person. My friend Allison was in there and I was going through to have my x-rays. Allison was having her treatments and Allison was down in the dumps and I cheered her up. I had two other people say thanks. There is a need. There is a—you're one of us but you're not— (Exclusion of the healthy)

R I know.

Nan You know, the contamination and another woman that I had seen at the same time I talked to Allison, who I saw a few weeks later going into Dr. B_______'s office for a checkup and she looked up at me and she was really sad and she smiled because she could identify.

R Is it almost like a community?

Nan Yeah.

R That the rest of us can't really understand or be a part of? Is that how it feels?

Nan Almost yeah. A reaching out—a need for something positive. I don't know.

Joe talks about his side of the experience:

Nan Yeah. In that hospital with those stupid, horrible robes on and this feeling that I had about cancer, it's not a nice place to be.

Joe I tell you. You remember—you talk about the feeling. I'll tell you the feeling that I get being in there. Do you remember seeing the movie about outer space and all the people coming out of their houses in the middle of the night in their pajamas.

Nan Yeah. I—

Joe Okay. I don't have cancer. I sit and I watch this and I'm like an outsider watching all these people leave to go—like robots.

Nan Um hum.

Joe You know. Shuffle, shuffle, shuffle down—shuffle, shuffle, shuffle. And I sit there and watch it—yeah, I get upset. I can't relax. I wander the halls. I want to get out, get out of that place. That's how I feel. And I don't have any disease. I don't, you know, but I'm sitting there and I'm watching all this and--regimentation—

You watch people, they walk down the hall [makes shuffling sound].

Marg	Maybe that person needs a smile or something.
Joe	You know. Sure.
Nan	Joe maybe they're like me. It hurts to lift your feet.
Joe	Well it's not that so much. It's their—
Nan	Yeah. I know what you mean. I know—
Joe	It's like they're going to the gas chamber, you know.
Nan	And that's just it, you're at everyone else's mercy, damn it all! I'm at your mercy, I'm at every doctor's mercy, I'm at every nurse's mercy, I'm at—you know what I mean. Strange territory. In my home I'm the chatelaine. I'm number one. Okay. And down there, I'm a nothing. I'm just a number. And, in fact, when the receptionist phones up to make a further appointment six months down the road, she doesn't give my name to the other department, she gives my number.
Joe	File number.
Nan	And she says at such and such a time on such and such a day, file number so and so will be—And then after that she says the name is ________. But the file number comes first. You are a file number who is put in a slot where they're going to take pictures on such and such a day. Okay. I'm supersensitive. I have a right to be supersensitive. (1:2:91-95)

Reflections

It has become elementary that the family caregiving experiences cannot be confined to one person or to one location. The caregiver follows the dying patient's needs and wishes to a large extent. The balance of power tips in the patient's favour. The powerlessness of the patient paradoxically becomes the force that holds the caregiver and moves the health care system to action. Charles' and Ruth's experience is an example of that reality. Charles and Ruth become the last key informants.

Charles and Ruth

The Patient and the Family are the Unit of Care

Charles and Ruth are two primary family caregivers who shared the twenty four hour a day, seven days a week caregiving to Charles' wife Nancy, who was dying of a rare kind of cancer, cancer of the gall-bladder. Charles and Ruth are selected as key informants because the locus of the patient's dying went from home (several months) to acute care setting (eight weeks) to the Palliative Care Unit (one week) and because their caregiving experience was shared equally. Studying Charles' and Ruth's experiences gives an overview of possible loci of care.

Ruth, Nancy's good friend, came to help Nancy at all hours both at home and in hospital and frequently "did the night shift." Although the relationship of Charles and Ruth to the dying patient was different, the feelings expressed were similar which again would lend credibility to their stories according to Glaser and Strauss (1967).

I met Ruth first and had several conversations with her before she invited me to meet Charles to hear his recollections of caregiving to Nancy as she was dying. Ruth and Charles were in agreement with Charles' impressions.

The caregiving experience is recalled through two hours of taping and several pages of memoes and field notes. I listened again to these tapes before writing about this experience. I remember Charles, an imposing man dressed in a suit and tie even though our afternoon session was to be informal. We met at Ruth's home. It was obvious to me that Charles and Ruth are usually self-sufficient and are used to being 'in charge.' They are articulate and assertive and expressed very clear opinions on their caregiving experiences and on needs that were met and those that were not met.

I interviewed Charles and Ruth at Ruth's kitchen table. Again, even though I was by now amassing quantities of data and had some idea of what I wanted to learn, it still seemed appropriate to start the taping with "Tell me about . . . ."

Charles' first comment was "Nobody knows what to do with these people." Later Charles added, "They [the system] have the theory down pat, but life doesn't read the text-book."

The Patient at Home

When Nancy was at home, they did not see themselves needing professional home care. Friends came in and brought food and flowers. "My wife was mobile and we were able to get out." Nancy's pain was troublesome but they tried several "painkillers" and finally settled on D_______ (trade name). It seemed to work best. However, dosage was a problem. As Charles said, "A tumour the size of a football doesn't go by the book . . . pain doesn't know that it should wait for dinner so you can safely give pain pills."

Charles and Nancy started to experiment with the medication to try to keep ahead of the increasing pain in her stomach. The increased pain, however, was from a developing ulcer in her stomach that was a result of the excessive use of D_______. The pain was not, as they thought, primarily from the cancer. Charles recalled the day he found out about his wife's real condition.

Charles remembered being downstairs making breakfast and hearing a loud thump upstairs. He rushed upstairs and found his wife on the floor, semi-conscious and obviously going into shock. Charles called the ambulance and had her taken to an acute care setting.

The Acute Care Setting

Charles wonders even now if he made the right decision. The diagnosis was "bleeding ulcer" and Nancy required immediate surgery. Charles had to sign the consent form to give permission to operate. Charles signed and eight weeks of post-surgical treatment began. As Charles said, the operation was successful and he was sure that the post-operative care was good but the problem was Nancy was dying of cancer. As Charles said, "We had a terminal situation here and they were treating her as though she was another surgical patient." He wondered out loud how she would have died if he hadn't called the ambulance and just had let her slip away in shock.

Charles quickly regained his composure and his rational self and continued on about the acute care setting. Charles said, "All I had to do was watch. It was likely not a catastrophe so far as the hospital was concerned but it was for me." Nancy would plead with Charles, "Do something."

Charles insisted that the high protein tube feedings stop. The feedings increased her discomfort. Charles said, "I was able to do that. I'm glad I did." Charles added, "Pain free level was not achieved although it apparently can be done." On the pain medication prescribed, "My wife went paranoid." "Paranoia or pain, that was our choice."

Ruth said, "They put the pain medication in the intravenous but they would have to find new veins as the old veins collapsed. They ended up giving shots into her legs but they were so edematous that her legs leaked around the needle. We thought she was incontinent but it was from the edema."

Charles said, "I wasn't trying to report anyone. I was just trying to coordinate something." In this situation, "you are all by yourself. I couldn't bring her home after surgery, not with all those tubes. I had no suction and I couldn't have given morphine." Ruth added, "There would be no one to answer those week-end questions." The two caregivers split the time they spent at the hospital feeling that someone needed to be with Nancy but feeling quite unprepared to take her home. The tape continues to divulge more details about the fears and frustrations experienced by these two caregivers. However, enough has been reported to give the sense of how it was for them as they sat and watched and waited.

The Palliative Care Unit

The other alternative for Nancy was the Palliative Care Unit. There was a waiting list but Nancy's situation was serious enough that a transfer was arranged. According to Charles, the last week of Nancy's life in the unit was a "god-send." Charles felt at last that "I was now part of the treatment. I was helping and I could help. The nurse would come in and say to me 'we'll help you get her out of bed.'"

Charles compared the two modes of care Nancy received:

> In the surgical unit the post-operative treatment was fine. It's not that science is wrong. It's just that you can't treat a dying patient in a surgical unit. The tempo is all wrong. I wanted people-people; someone to sit with me and say 'anything you want? You know, bedside manner.'

Charles expanded on why the Palliative Care Unit worked so well for him. "It was," he said, "a community of dying people and a community of family members." (The two communities are served)

As Charles said, "I wanted a hand on my shoulder not a pat on the head." Charles talked on about the Palliative Care Unit and the differences that he found in the environment. I'll report his comments in point form.

The Palliative Care Unit

1. Community of dying and community of family members. "We talked about all sorts of things. You know, when people are dying they're not morbid."

2. Communication. "They weren't afraid to use the word cancer. They never asked 'how are you?' or said 'I know how you feel.' They would explain things to me. We don't want patronizing. We were treated like any other

human being."

3. The place needs to be small. "Manpower is an expense but I would gladly have paid to have had my wife in the unit as long as required."

4. Care for the dying requires special people. "You wouldn't open a surgical unit without a surgeon would you? It's a field of medicine that's not touched . . . I kept trying to find solutions . . . I didn't know such a place existed."

5. Familiar staff/available staff. "We got to know the nurses. I could ask 'stupid' questions."

6. The environment. "There were volunteers to sit with you and bring you a cup of tea. I used to wheel Nancy around the ward after she got her pain controlled. We could stop here and there and talk with people. It was cheerful—hopeful."

7. She was not in pain. "They put this drip into her shoulder that even I could have managed. She was comfortable."

Although neither Ruth or Charles had read about hospice or palliative care, it was interesting to note the similarities between Charles' list of necessary qualities of care for the dying and the hospice way of providing care.

I asked Charles and Ruth about home care at the last stages of dying. They thought that they could be taught and could cope with the technical end of things particularly if they had support.

Living with a Dying Person

Charles talked a little more about living with a dying person and its effect on one's thinking:

> Everybody is going to die. Nobody plans it though. What is important is comfort and quality of life, not quantity. I told my son not to let them manhandle me into one of those mechanical devices. I'm not interested!
>
> When you know someone is going to die it changes your life. You feel sick. You feel like you're going to throw up. You then become concerned. Then you accept or rather you adapt. We were given a ball park figure between six months and two years. At least they were honest.
>
> Right away I thought let's travel. Then I thought, "Can she stand it?" You keep looking at them sort of sideways. You wonder as you look, "Will she be here next year?" What can I do? I mustn't show it. They cry. You cry. You get over it. Friends help.
>
> You are ambivalent; torn between keeping them and letting them go. Everybody's different.
>
> You try to re-build sort of the Phoenix out of the ashes. You never forget. The pain goes away but the scar is always there.

Charles and Ruth are the last key informants to be presented in this study. The stories of family caregivers and patients that have been described demonstrate the similarities and at the same time, the uniqueness of each person's way of living through the dying process.

A final reflection on the research process is in order.

Reflections on the Research Process

Assessment of Data Gathering Methods

In a more traditional inquiry much of the data collected would be considered dross or wasted material. Many times the primary family caregiver apparently did not stick to the question of "What is the experience of caring for the family member who is dying at home?" One critic who scanned the data shook her head and said "But he talked mostly about the dying patient. You must keep him on topic—his experience." Because the criticism came early on in the data collection, I doubted the method I was using. Perhaps I should direct the time that I was with the informant. Ask questions. Get to it. My transcripts were filled with R: "Um" or R: "Uh huh" or worse R: followed by a convuluted paragraph of an attempt to lead the informant away from his story.

Three points about qualitative research came clear:

One: Glaser and Strauss (1965) were correct. Don't share your data prematurely. Work with the data until you gain confidence in the method.

Second: Be cautious at labelling any data 'dross.' The material on the dying patient which seemed to the critic to be excessive in fact became the insight albeit belated, that of course much of the talk centered around the patient. The patient was central to the family caregiver's life. The second insight that occurred later in this regard was that the dying patient was not central precisely but was more like an encompassing preoccupation that totally surrounded and engulfed the primary family caregiver.

Third: I believe in the power of the story, particularly when the story is heard and experienced with the informant on site. As it happens, I could not help becoming involved, even embroiled in the informant's process and was relieved to read Rosalie Wax's account of her over-involvement with informants (Wax, 1952). Intervening with the system on the family's behalf as I did on a number of occasions had a precedent in Wax's research activities.

Reciprocity

Another interesting development that occurred during the time in the field was an unselfconscious reciprocity. The reciprocity that seemed to be natural while visiting in the informants' homes now seems to be too trivial to report. However, even that fact is datum. Something natural and easy and timely is lost and becomes artificial when talked of from a distance. An example of the 'trivial' reciprocity was the hospitality shown at each visit. Always, the first thing offered was tea or coffee, no matter how busy the day or night. I, in response, began to take little gifts, such as a jar of homemade jam or a book I thought the caregiver would enjoy. For example, the day that Joe and Nan were to see Dr. Kübler-Ross, I dropped off a bottle of wine which they used in their celebration when they returned home with their friends. "What is good is given back" (Hyde, 1979:vii).

Relationship with Informants

The relationship that developed with informants was not exactly friendship but rather more like the relationship one forms during a shared intense experience. One vows that "I'll write" or "I'll be in touch." However, time and events intervene and interfere. There is the feeling that a phone call to the informant would be welcomed but is not necessary.

The Necessity of Time and Space

I may never again have the luxury of time to do this kind of research. Two years is a long time. The helpful win of a dissertation fellowship supported the first year's work and the second year's expenses were offset by the work done at Alberta Hospital Association during my self-imposed retreat from the field. The other luxury is space and a tolerant family. Transcripts and tapes stayed neatly encased in plastic bags at another location but all other data had a tendency to creep out of the downstairs office, up the stairs, into the living room and upstairs 'office.' I confess to general untidyness but this research was particularly right-brain and disorderly. Insights popped up at inopportune moments and were captured on scraps of paper. These 'scraps' were later fastened into a huge navy blue book that I purchased because it would stand out in the crowd of articles and books that were loaned and purchased. A general tidy-up is longed for at the time of this writing. The end is in sight.

The Necessity of Reflection on the Research Process

Journal notes such as these notes are essential to the health and sanity of the 'solo' researcher. The journal becomes an alter ego, a friendly conspirator and confidante. Much of the writings will not bear the light of day as they were at times libelous, scandalous, grossly humourous at least to the author and in general necessary but inconsequential meanderings through the subterranean recesses of the author's mind.

Chapter 5

In Chapter 5, I report findings as they relate to themes and themes as they fit with a proposed Client Assessment Form. Hypotheses are developed and related to a developing evaluation framework. Recommendations that are tied to health care service providers', administrators' and educators' concerns are offered.

Chapter 5

SUMMARY OF THE RESEARCH PROCESS

In Chapter 1, the domain and purpose of the study were described in detail. Hospice or Palliative Care was the chosen domain of the study and this rapidly growing concept and philosophy of care was traced from its roots to the present. Hospice, which started as a counter-culture movement of care for the dying, has currently reached the point that health care administrators and government policy planners are demanding 'hard' evaluation studies.

Hard/quantitative evaluation studies have been undertaken in the United States and have not found any significant difference between Hospice and other more traditional methods of care for the dying. However, pioneers in the Hospice movement such as Mount and Scott doubt that quantitative methods alone can capture the essence of Hospice Care.

The need exists for the development of an evaluation model or framework that reflects the Hospice philosophy and is responsive to patient and family needs. The reader is reminded that this is not an evaluation study. Rather, the development of a Responsive Evaluation Framework became a major objective of the study. The construction of a framework that is preliminary to a comprehensive evaluation of hospice care reflects the state of the art of hospice evaluation.

Deliberations concerning an appropriate paradigm and method of research for this inquiry were reported in Chapter 1.

In Chapter 2, Hospice and Hospital were contrasted in order to demonstrate the basic differences in philosophy and service between these diverging branches of health care delivery. The literature was reviewed to further delineate a portion of the domain of Hospice that would be likely to provide useful new information. It was discovered that the primary family caregiver providing or managing care for the patient who is dying at home, has for the most part been overlooked by researchers. The focus on primary family caregiver that was chosen for this study was justified.

Chapter 3 further explicated the research method and process. Issues such as ethical concerns, validity and reliability of qualitative research were raised and addressed.

In Chapter 4, findings from eight key informants and a variety of ancillary informants were reported in detail and analyzed for categories and themes. The task remains in Chapter 5 to translate the findings into a format that will render the findings useful to service providers, educators and administrators. The literature has again been searched and used for the purpose of strengthening the lines of communication between the informants and the service providers, educators and administrators who are charged with developing Hospice Care services and personnel.

To set the context for the remaining portion of Chapter 5, Mount's interview with the editor of the Alberta Foundation for Medical Research Newsletter is again excerpted to point out the heroic proportions of the task of caregiving for the dying patient that is being required of family caregivers and home care and in-patient professional staff. Mount (1986:14) reminds us:

> These are our sickest patients with complex needs that require competent, skilled medical care. We are not just talking about sentimentality and hand-holding, but complete medical care, adding to that the psycho-social and spiritual issues.

Conclusions from the Inquiry

What started out to be an inquiry into the family perspective on dying at home turned out to be a whirlwind tour of the health care delivery system as I followed the family caregiver who was following the patient's dying trajectory. I discovered that dying at home does not necessarily mean a quiet and orderly death at home.

About Hospice/Palliative Care for the Dying

In contrast to the findings of the National Hospice Study that reported "no significant difference" between hospice and traditional methods of care for the dying, I found out that even the hope of being under the very small umbrella of available hospice care was of paramount importance to informants faced with the cold prospect of dealing with the dying experience unprepared.

There is "something more" about the hospice philosophy/concept/idea that fans a spark of hope in dying patients and their family caregivers. Nan writes to England and to Washington and mobilizes a visit to the local PCU in an attempt to secure a place for her dying that will be easy on Joe and allow her to maintain some semblance of control and provide an escape from "demoralizing and debilitating" pain. Salim reads of a competent doctor who will actually sit down and talk to a family caregiver; then he shakes his head in disbelief that this could happen.

Jennie is relieved to find that Mrs. J will be comfortable most of the time and will not "go out screaming." Nicole, Charles and Ruth knew something had to be done for the patient's pain. Experimenting with scotch and painkillers or increasing the dosage of painkillers that had potent side effects were tough responsibilities for lay persons to carry. The relief these family caregivers felt when the patient was safely ensconced in the PCU could be felt if not measured.

Bert was relieved at the assurance that he and his father were flying toward a Boston hospice program when they boarded the plane home. Alice thought maybe if there had been a hospice program her father would have signed himself in for help rather than running for cover.

The hope for the miracle of cure becomes hope for a miracle of care. Patients and families believe that when pain and symptoms of the disease and side effects from treatments and medications are controlled, the patient and the family caregiver are freed to live toward a good death.

It was found that hospice/palliative care to the family caregiver means feeling (and wanting) the supportive, encouraging "hand on the shoulder" and not experiencing (and needing) a patronizing "pat on the head."

The analogy is pushed further to discover from the findings what the professional caregiver's "hand on the shoulder"/"pat on the head" means to the family caregiver and to the patient. Hypotheses about the caregiving experience are developed that are "like a perspective or point-of-view" (Diers, 1979:69). The hypotheses are developed within the framework of categories that became evident from initial line-by-line analysis of the data. The message from the informants is directed to practitioners, to administrators and to educators who are involved in organizations charged with health care concerns.

1. Informants' Expectations of the Health Care System
    1.1 Expectations of the system are at first unclear and not well defined. Family caregivers piece together a patch-work of past experiences with the system, with coping strategies that more-or-less worked for them in past crises and an instinctive trust that somehow they and the system will manage if they can get it to work.
    1.2 Expectations include basic rights/needs and the desire for "something more" for the patient and caregiver who are "only going to do this once."
    1.3 The desirable "something more" is reasonable; not, for example, the desire for a miraculous cure. "Something more" is akin to quality care/quality of life/dying with dignity. It is related to the way health care is provided. (As Nan put it "Someone to go to bat with me.")

2. Informants' Perceptions of the Health Care System

The Health Care System is talked about by caregivers and by patients as an entity in itself but the 'System' means the health care professionals with whom the family caregiver/patient has had contact in the past and the present or the setting in which the care has been/is provided. The professional referred to may be any member of the health care team which includes volunteers, doctors, social workers, psychologists, nurses, secretaries, homemakers, physio/occupational therapists and chaplains.

2.1 Positive Perceptions

2.1.1 The family caregiver/patient appreciates and responds to the professional who is competent ("the technique") and who is caring ("the art").

2.1.2 Collegiality is appreciated ("We are all in this together") balanced by the knowledge that the professional has a unique and necessary contribution to make to the caregiving experience.

2.1.3 Human scale proportions of setting are appreciated. Home with modification or relatively small units are appropriate.

2.2 Neutral Perceptions

2.2.1 The family caregiver/patient needs/wants housecalls by preferably the doctor but understands the difficulties of time, money, inconvenience.

2.2.2 The family caregiver/patient would like to have a 'real' cure but after the initial shock and panic accepts the offer of 'real' care.

2.2.3 Family caregiver/patient understands the problem with "the budget" but want care tailored to their individual needs.

2.3 Negative Perceptions

2.3.1 The family caregiver/patient becomes angry at the professional perceived

: to have an attitude of superiority

: to be too busy to listen

: to be too busy/too distant/too irritable to explain diagnosis and prognosis in an appropriate manner.

2.3.2 The family caregiver/patient is fearful of a setting that

: is automated ("like Chrysler")

: segregates the two communities (patients to the right, family to the left)

: is inflexibly bound by rules and regulations.

3. Informants' Coping Strategies

3.1 The family caregiver is compelled to react/respond to the increasing powerlessness of the dying patient. Choices include not only the explicit act but also the implicit consequences of the act. Choices vary from reactions such as refusing to act (guilt/remorse) to the response of letting go/going with the patient's needs and timing (finding one's own strength).

3.2 Family caregivers do not make one choice and stay with it but vacillate, depending on internal and external conditions. At times the system's patronizing "pat on the head" would be welcomed if it bought release from the burden of caregiving.

3.3 The family caregiver does nothing exclusively unilaterally. Choices are made in cooperation/collaboration with the patient or in spite of patient's needs. The patient and family caregiver is the unit of care and focus of research.

3.4 The family caregiver may become artful and skillful at caregiving through necessity using common sense. The burden is eased if the caregiver is provided with an appropriate level and kind of information that is made available and accessible to both patient and caregiver.

3.5 Coping strategies include responding to physical and emotional needs of the patient.

3.6 The caregiver does not know what he/she needs to know, not because he/she is incapable or incompetent but because the dying experience is unfamiliar territory and the professional holds most of the available maps. Earlier interventions from discharge planners in acute care settings in close liaison with home care personnel would change the 'management by crisis' style of coping strategies into a less stressful care plan.

4. Informants' Support Matrix: What is Available; What is Needed

4.1 Family caregivers are *not* *either* Care Managers *or* Care Providers but do varying amounts of tasks inherent in both roles depending on the caregiver's availability, but more importantly, depending on the caregiver's attitude toward caregiving which is values-based and on the resources at hand which is situational.

4.2 Support matrix is deemed a positive source of strength or a negative drain on energy *from* the caregiver's/patient's perspective *not* from the professional perspective. Numbers do not necessarily add up to strength.

4.3 Support is tailored to family space, privacy needs and preferences but it is recognized that the health care agency has limited resources. Flexibility within reason is the appropriate professional response. Explanations about limitations are understood, appreciated, and tested.

4.4 The support matrix provides a network of care/support that

: extends from the acute treatment centre to home and community and back again to the acute care setting or palliative care unit.

: extends from diagnosis of disease through treatment, remission, terminal care, death of the patient and aftercare for the bereaved family if necessary.

: is there, in place, available, accessible and precedes the needs of the patient/family.

4.5 The support matrix provides respite care for the family caregiver. Respite means the luxury of sleeping in once in a while, or getting out to shop, or free time to get the winter tires on. It is not a week-end escape. In late stages of caregiving the family caregiver does not escape. Respite is a gift that is not stuck together with red tape.

4.6 Professional care is available as back-up 24 hours a day, seven days a week. Back up care is a phone number and the knowledge that first, information would be available, if needed, then a hands-on helper would come if necessary. The available help is not abused. Family caregivers tend to cope with the crisis and call for reassurance in the morning.

5. Emotional Costs/Emotional and Other Benefits for Informants

5.1 Family caregivers experience overwhelming physical and emotional stress that can be tolerated even unnoticed when

: there is a foreseeable end-point; the end-point being a good death of the patient.

: there is a properly deployed support matrix.

: anxiety is reduced by doing for the patient and knowing that the caregiving is perceived as helpful by the patient and considered to be correct by the professional.

: there is an appropriate level and kind of information available and accessible to the caregiver.

5.2 The corollary of 5.1 is also evident from the findings.

5.3 A 'good death' means freed of pain for both patient and caregiver. (A subtle difference from the unrealistic goal of pain-free dying.) The caregiver benefits by participating, by doing hands-on care, by being with the patient as evidenced by informants' experiences. However, all persons labelled caregiver may not be able to do the more delicate care that is necessary.

5.4 Death at home is considered to be a success by caregivers which has positive and negative implications. Death at home is positive if it achieves enhanced family relationships. Death at home may become an unrealistic goal which diminishes the potential good if the patient and family are unable to 'do it.'

5.5 Well supported family caregiving may allow time for reminiscing, celebrations, humour, completion of unfinished business worked through by doing and being with the patient even if "The Big Talk" never happens.

5.6 Celebrations, humour, completion of unfinished business are considered to be the domain of the spiritual. Typically, heavy spiritual 'matters' such as death, meaning and purpose in life are probed by metaphor or let alone until after the death of the patient.

5.7 Lighter aspects from the 'domain' of the spiritual when let alone become fluid and infiltrate the dying experience, pop up like an unexpected gift or bonus. Time out.

5.8 The bereavement visit/telling the story becomes a way of weighing the experience and integrating many of the 'its,' i.e., the questions, the fears, the mysteries of life and death that were challenging the patient and the caregiver during the dying experience.

Informants' Need for Information: Hypotheses to Theory

The need for information that is not only available but is also accessible has been left to the end and is emphasized because of the pervasiveness of this category. The need for information becomes part of a developing theory.

Throughout the inquiry, I found large gaps in information that ranged from not knowing about what services were available, not knowing how to obtain the services needed or even more basic, not knowing what services would be really helpful and necessary.

The 'System' is asking family caregivers to take on the care of our sickest patients and for the most part we have not yet been readily available with "maps and charts of the territory." Even if the family caregiver is lucky enough to live within reach of Laurie and is covered by the Palliative Care Home Program at SHU, or is on the waiting list at the Palliative Care Unit, there is a need for "something more."

Again picture Joe and Nan

: finding out that the cancer is back by a letter coming through the mail slot

: isolated from each other because they communicate in metaphor and code and most often misinterpret the message

: sense that they can't do it all themselves but are unsure of how to share the load

: left to do their own discharge planning due to a gap in information.

Picture Salim: educated, intelligent, a linear thinker who needs facts and will find them in books and apply them inappropriately to real life and dying.

Picture Jennie: the successful caregiver who had the most extensive support matrix, the ability and the resources to support Mrs. J's good death at home. Even Jennie needed information about home nursing, about equipment and about many of the details that make home care possible.

And Nicole: caught in a crossfire of loyalties and responsibilities, taking advice but unsure about how to translate the advice into action. Information about pain control and linkages to sources of help were required.

Picture Bert: the entrepreneur temporarily stalled by his allegiance to family culture and the p[P]rovincial rules and limitations of care that we all understand but that don't make sense at first when you are embroiled in caregiving for an irascible father. Information about pain control and international hospice services helped.

Or Alice: one pictures Alice running, chasing the system, informed about the statistics of the treatability of cancer of the lip but constantly frustrated by her father's intractability and the System's shrug.

Charles and Ruth

: stuck with those week-end questions, trying do-it-yourself pain control. "Pain hasn't read the book."

: isolated and feeling "patronized" at the acute care setting then

: feeling "the hand on the shoulder" at the palliative care unit, being kept "in the picture," informed, neither abandoned to find out for yourself nor smothered with sentimental, empty words of false hope.

I returned to the literature on caregiving for a dying person. C. S. Lewis (1961) became the author of choice, the author who best reflects the pace and quality of the family caregiving experience. Other authors such as Parkes (1972), Kreeft (1979), Albertson (1980), Bowlby (1981), Grollman (1981), Kushner (1981), Moffat (1982) and Viorst (1986) were re-read. Each author had something to offer but it was Lewis to whom I returned. Lewis describes the pace and quality of this time of tangling with the dying experience. Lewis (1961:70) writes about "the spring-cleaning in his mind" about good death that he learned from several months of pondering the death, at home, of his wife.

> I'm almost scared at the adjectives
> I'd have to use. Brisk? cheerful?
> keen? alert? intense? wide-awake?
> Above all, solid. Utterly reliable.
> Firm . . . Pure intellect . . .

At first this doesn't make sense. Perhaps Lewis is denying? Boulby (1985:53) reviews a video of an interview with another caregiver and writes "[The caregiver] is articulate in her description of her feelings but is unbelievable because she does not demonstrate her feelings."

Interestingly, Lewis (1961) wrote under a pseudonym and called his book A Grief Observed. The movie made about his caregiving experience for his dying wife is called Shadow Lands. I think of Salim as he watched his caregiving experience going on like a "bad movie."

Lewis, however, is making the point that although we love, feel attached, and grieve painfully for the loss of the dying person, there is a sense of release/relief when we, as one might say, put our minds to it. Putting our minds to it is not related to the Puritanical concept of mind over matter, or stifling the emotions. Having and using information is simply necessary to find one's way through the caregiving experience and to make sense of the emotions that swirl up from the dark, unknown part of one's being. There is a "spontaneity and a forthrightness" about the adult patient's and family's perspective on dying that is often found in the child facing death (Bull, 1985:44). Adults have learned to mask this forthrightness.

Kübler-Ross (1978:103) puts the needs of the intellect—the mind—back into perspective:

> It is known that there are four quadrants comprising the human being's personality—namely, the physical, spiritual, intellectual, and emotional aspects—and people can [do] well if these are in harmony.

How then do the findings from the informants, from Lewis, and Kübler-Ross fit with the definition of Palliative/Hospice care for the dying?

Palliative care defined:

> "Palliative care" refers to programs or services that provide care to those patients for whom treatment aimed at cure and prolongation of life is no longer appropriate but for whom therapy aimed at improving the quality of the remaining life is the primary objective. Palliative care offers therapeutic services designed to address the physical, psycho-social and spiritual needs of dying patients and their families. (Palliative Care Services in the Hospitals: Guidelines, 1981:2)

Hospice defined:

> [Hospice is] . . . a medically directed, nurse coordinated program, providing a continuum of home and inpatient care for the terminally ill patient and family. It employs an interdisciplinary team under the direction of an autonomous administration. The program provides palliative and supportive care to meet the special needs arising out of the

> physical, emotional, and spiritual, social and economic stresses which are experienced during the final stages of illness and during dying and bereavement. This care is available 24 hours a day, seven days a week. (National Hospice Organization, U.S.A.)

Re-reading Standards of Hospice Program of Care (Appendix 1) and Assumptions and Principles Underlying Standards for Terminal Care (Appendix 2) is further motivation to suggest making the implicit explicit. Providers of Palliative/Hospice care are cognizant of the need for information. Perhaps it goes without saying. But, perhaps not if you believe that words have power to inform practice.

Based on the findings of this inquiry, and the assumption that it is helpful to make the implicit, explicit, I propose that the definitions of palliative/hospice care be modified to include the intellectual aspects of the patient/family caregiver. The definitions as proposed would read:

> "Palliative care" refers to programs or services that provide care to those patients for whom treatment aimed at cure and prolongation of life is no longer appropriate but for whom therapy aimed at improving the quality of the remaining life is the primary objective. Palliative care offers therapeutic services designed to address the physical, psychosocial, intellectual and spiritual needs of dying patients and their families. (Canadian Modified)

> [Hospice is] . . . a medically directed, nurse coordinated program, providing a continuum of home and inpatient care for the terminally ill patient and family. It employs an interdisciplinary team under the direction of an autonomous administration. The program provides information, palliative and supportive care to the patient and family to help them

> meet the special needs arising out of the physical, emotional, and spiritual, social and economic stresses which are experienced during the final stages of illness and during dying and bereavement. This care is available 24 hours a day, seven days a week. (American Modified)

Latimer (1985:37) lends support to the author's contention that a change in definition is a useful move: "The very wording of a definition of palliative care will influence its practice, perception by a system, and therefore its impact." Latimer (1985) makes a further claim that suggests that findings from this inquiry that express the needs and wishes from the patient/family perspective are timely and significant. Latimer (1985:36) claims:

> Many health professionals are beginning to place the needs and wishes of patients and families ahead of their own and those of the institution or agency where patient and professional meet. This results in more flexible, humanistic health care practice in which caregivers and the system are beginning to bend a little. Certainly, we still have a long way to go.

The findings from the patient and the family caregiver become the basic building block of the Responsive Evaluation Framework.

Input A. The Family

DYING PATIENT'S	Perception of the Situation
PRIMARY FAMILY CAREGIVER'S	Lifestyle, Context Wants, Needs, Abilities, Support Matrix

Significance of the Findings to Practitioners

The caregiving experience is lived in the front lines. The front line professional is frequently the home care nurse. The Family Caregiver's Assessment Form is offered as a check-list to the front line professional. The form has been through several stages of development since its inception in St. Christopher's Hospice as a Bereavement Assessment Tool several years ago. The most recent evolution came as a result of Jennie's critique and additions. Content has been expanded to include the basics, i.e., the assessment of the need for information re home nursing skills as well as the need for information about communication difficulties and other sources of stress in the physical, emotional, intellectual and spiritual domains.

The submission of the Assessment Form is prefaced with a point form reprise of the elements of information as they surfaced from the themes identified in Chapter 4.

Meaning of Information to the Primary Family Caregiver/Patient

1. Information means being given back some power and control so that negative ways of regaining control are not necessary.

2. Exchange of information encourages talk: talk may lessen fear and isolation and lead to communication between patient and family caregiver and the health care

professional.

3. Information about diagnosis/prognosis that includes small details and excludes false hope is useful. Anxiety may cloud hearing the information. Follow-up is required.

4. Information in the form of advice should be accompanied by follow-up and help.

5. Clues as to a way information may be made accessible may be disguised in metaphor. Each individual is unique with differing values, needs, attitudes and expectations. Sometimes the unique quality of the person is encoded in metaphor.

6. Theory needs to be unpacked and redistributed in practice-oriented layman's language.

7. Giving and receiving information takes time initially but saves time long-term.

8. Lack of available and accessible information leads to unnecessary drains on the patient's and family caregiver's energy reserves.

Mah Wren (1984:15) in the Proposal, Design and Management Plan for the Edmonton Home Care Palliative Care Program writes: "One of the major responsibilities involved in hospice care is related to including building skills, providing information to family members." The Family Caregiver Assessment Form that follows may serve as a reminder of components of the information identified for us by the informants in this study.

The Family Caregiver's Assessment Form is presented in the following order:

1. Family Caregiver's Assessment Form as it was presented to Jennie. Jennie's additional comments are used in the second phase of the development of the form.

2. Family Caregiver's Assessment Form (Page 1) as it evolved from Jennie's comments. Themes which persistently surfaced from the analysis of other informants' experiences are also used to develop the assessment form. Page 1 guides the assessment of caregiver deficits.

3. Family Caregiver's Assessment Form (Page 2) is the companion piece to page 1. Page 2 guides the assessment of caregiver's strengths. Both assessment forms are to be thought of as guidelines, or check-lists. Data are collected by the professional caregiver. The information is from the family caregiver's perspective.

The Family Caregiver's Assessment Form fits into the Responsive Evaluation Framework as Input B: The Professional Caregiver's Domain. The Form is offered as a tool to assist in developing the knowledge base of the professional caregiver.

Professional Health Caregiver's
Perspective Based on Knowledge

Input B: The Professional Caregiver

Family Caregiver's Assessment Form

(Complete During Home Visit)

PROBLEMS FROM CLIENT'S PERSPECTIVE: (Circle appropriate words)

PHYSICAL: Eating: too much/too little lost weight   Sleeping: too much/[✓ too little]

Illness: actual/[✓ feared]   Energy level: reduced/[✓ increased] - need to keep driving

Drugs: excessive alcohol/prescription/non-prescription sluggish

Pain/discomfort/tension: muscular/systemic

pulled muscle when lifting feared unable to carry on

Exercise/Recreation Yes/No - Why?

Comments/other: ulcers acted up during this time and had to take copious amounts of Maalox

EMOTIONAL: (Psycho-Social) Isolation: lack of contact with others/painful contact with others

Crying: excessive/inability to cry no - just the opposite

Fears: of madness/of [✓ breakdown]/of haunting memories/of the dying process

Dreams: pleasant/[✓ unpleasant]/nightmarish

Concern about ability to handle the situation.

Relationships: difficulty in maintaining relationships with family/[✓ with friends]/difficulty in coping with children's grief/[✓ difficulty in explaining death to child]/difficulty in controlling child's behavior

Too busy to keep up relationships with friends.

Comments/other:

Would ask health nurse all necessary questions regarding medication, nursing patient etc.

INTELLECTUAL: Need for information re: : dying process: pain control - Home nursing - feeding - toilet - bathing - turning - medication - giving needles - bedmaking

grieving/loss - How to cope
- How to explain death to others
- Explanation of normal grieving

All needed

: post-funeral questions - financial worries/concern with rituals or community expecations

Comments/[✓ other]:

Grandma's acceptance of her impending death helped us all.

SPIRITUAL: Death - seeking to explain or understand death/doubts concerning after-death

Belief: other spiritual or religious problems/doubts concerning own goodness or self-worth/doubts concerning other's goodness or self-worth

Underlined belief in spiritual rather than material things.

God: doubts concerning the goodness of God/or the existence of God

reinforced religious convictions

Lack of meaning/or purpose in life/No sense of personal future

Participating in what life has to offer rather than as onlooker

Comments/other:

FAMILY CAREGIVER'S (FCG) ASSESSMENT FORM

Problems from the FCG's Perspective: FCG Deficits

PHYSICAL:
Eating: too much/too little
Sleeping: trouble getting to sleep/insufficient length/ insufficient depth/excessive fatigue
Smoking: no problem/the usual amount/excessive
Drugs: alcohol/prescription/non-prescription
Illness: actual/feared
Energy: reduced/increased to hyperactivity
Recreation: no time/no desire

EMOTIONAL:
Isolation: lack of contact with others/painful contact
Crying: excess/inability/fear of not able to control
Fears: of breakdown/of dying process
Anger: feelings of excessive responsibility/lack of privacy/ lack of space
Dreams: more frequent/unpleasant/nightmarish
Panic: feelings of inability to cope
Relationships: difficulty in maintaining relationships with family/with friends
difficulty in coping with children's grief/ with explaining death to children
difficulty in understanding family's or friends' behaviours
Time pressures: patient related/family related/work/community related
Space pressures: inappropriate help/too much help/ lack of help

INTELLECTUAL: Need for information re:

Physical care for the dying person: bathing/nutrition/turning/ bedmaking/lifting/ constipation/mouth care/ wound care
skin: dryness, pressure points, 'sweats'
medication: charting/measuring/observing results/giving injections/obtaining narcotics
dying process: signs/symptoms/interventions
task sharing: making agendas

Emotional: communication: with dying person/others/abiliity to say yes/no/own grief, feelings of loss/ resentment/guilt/fear of dying/death

Other: coping with present job or future work/role reversal tasks/financial advice/insufficient money/accommodation/ equipment access/equipment use/home death vs. hospital death/funeral arrangements

SPIRITUAL*:
Death: seeking to explain or understand death/concerns about after death
Belief: spiritual or religious problems/doubts or anger concerning goodness or existence of God/doubts concerning own goodness or self-worth

*Spiritual concerns may not be evident until bereavement visit.

(Based on St. Christopher's Hospice Assessment Form modified by findings from current study.)

FAMILY CAREGIVER'S SUPPORT MATRIX

FAMILY MEMBERS: (Relationship, approximate age, location)

____
____
____
____
____
____
____

COMMUNITY SUPPORT: (Include friends, neighbours, groups)

____
____
____
____
____
____
____

COMMENTS ON ABOVE: (Encourage honest appraisal of potential helpfulness of the above from the family caregiver's perspective)

____
____
____
____
____
____
____
____

2 of 2

The Administrative Response to Findings

The findings from the inquiry (Input A) have been developed into a practical guide to assist the professional caregiver assess the needs of the family caregiver (Input B). It is assumed that patient/family caregiver's deficits are greater than available strengths or the professional caregiver would not be involved.

Assessment of Needed Input

Stage three of the developing framework is in a sense the professional caregiver's return to the office to assess the needed support. Data from the Assessment Form may prove helpful. Patient and family problems/ deficits are considered. Then patient and family strengths are identified. From the findings a sense of the real deficiencies of the family during this vulnerable time are observable and potential health care interventions become clear (Input C).

Family Problems/ Deficits - Family Strengths = Family Deficiencies = Potential Health Care System's Intervention

Input C: Assessment of Needed Support

Two points must be stated:

1. Assessment of Needed Support is not static. The initial reading gives the professional caregiver base-line

data. If the service is to remain relevant, follow-up is necessary but will be less time-consuming as a relationship develops with the patient and family caregiver.

2. There are many patient/family "units" of care. The professional caregiver and the administrator meet at this point. Policy, scarce resources and other organizational concerns must be considered.

Speaking of the patient/family as a unit of care seems far removed from the individual people who were introduced in Chapter 4. Administrative distance from the field is a mixed blessing. Distance makes hard decisions less likely to be based on personal feelings (Objectivity of Program). However, distance also leads to decisions based on out-dated policy that is no longer related or responsive to the "citizen." (Policy derives its meaning from the Greek for "from citizen," from "to make known" (Weekley, 1967:1118).) (Relevance of Program)

It is timely to insert another story, Mrs. W's experiences with the Health Care System. The story is instructive concerning "citizens'" needs and the Reality of the Possible. (Reliability: Close to the Data)

Mrs. W and the Health Care System

In the Edmonton Journal, September 24, 1986, there was an interview with an Oncologist which triggered an idea that is not yet well enough developed to be a full-fledged recommendation. The Oncologist is "heartily sick of patients complaining about their doctors . . ." The quotation was read two days after I had received a late night phone call from Mrs. W, an eighty-three year old friend. Mrs. W had undergone surgery for cancer of the colon in the summer and had done "quite well," i.e., she woke up from surgery, felt the dressing and found that she did not have a colostomy and that the surgeon thought that he had "gotten most of 'it.'"

Over the past few weeks Mrs. W had been having dizzy spells. She went to her oncologist, "waited two hours and was seen for about three minutes." She had told him about "my dizzy spells" and he suggested that she go back to her own doctor. Mrs. W did this and told her general practitioner about the spells. He said "if anything is wrong, the oncologist would have caught it. You are over eighty."

Although this lady is a very competent person, brought up in a physician's household and the widow of a doctor, she felt very shy of "speaking up" to the doctor. Worse, she had been afraid of burdening her only relative, her daughter, about her two fears; one of which seemed as bad as the other. The fear she mentioned first was that of bothering her daughter and me with her worries. "You might think that I'm making too much of being an invalid" (connotes in-valid?). Second, after much talk, it slipped out that she thought that maybe 'it' had come back and had resettled in her brain. She didn't say the word cancer.

We talked about all sorts of possibilities. We went over other things that could be going wrong that would be quite easily fixed. (Giving hope)

When it comes to giving hope, it must be realistic hope. My friend is intelligent, has lived a very long time and is a realist. Platitudes would not have cut any ice with her.

The conversation continued: "Would you call my daughter?" "Yes," I said, "I would. What do you want me to say?" She didn't want me to hurt her daughter's feelings in any way, but perhaps I would suggest that her daughter see the general practitioner on her behalf, and mention rather casually some of the other things that we thought could be causing the dizziness. I said I would and called her daughter whom I knew slightly. (The need to be careful)

As a matter of fact I was aware of the need to 'be careful.' Remembering Joe and Nan, I thought that one takes a chance when one interferes in the delicate balance of family relations. However, the call was completed. The daughter went to the general practitioner and she in turn discreetly passed on the information and the need to, or perhaps I should say, the request for, further investigation. Doctor/family relations are also delicate. As my friend had said, "The doctor is a nice man and I do need to have good feelings between us." This story has a happy ending as a change in heart medication and the odd tot of brandy in warm milk made a considerable difference.

To make the point, it is necessary to get back to the interview in the Journal (September 26, 1986, p. B2). The quotation from the oncologist specialist is as follows:

> The local oncologist said: "I am heartily sick of patients complaining that their doctors never listen to them . . . and I get more tired of telling them: 'Your doctor would love to talk to you and spend time with you, but time is money and there isn't enough money in the service.'"

The Meaning of the Story to Administrators of Health Care Agencies

If time is money and money buys health care service and it is agreed that at least some patients are not feeling well served, then what can be changed in the ratio of service? Time—money?

Time. Time, it appears, is not so linear and unchangeable as one would think. Time is also an attitude. However, attitudes are difficult to change. Getting one's timing in 'sync' with the patient's and the family's may be a long range task of the health care education system. Professional caregivers need to be taught the value of quality time. Administrators of health care services must also provide encouragement and approval for time spent with patients and families by service providers.

Patients and family caregivers may not hear what the physician says about the diagnosis/prognosis because of anxiety but the fact that the professional looked at the time while talking is well remembered and is perceived as "I'm unimportant."

Administrators of health care agencies are in the ideal position to live up to their names. Ad-ministration means toward-service (Weekley, 1967:14,934). Administrators' main raison d'être is to make it possible for the service provider which includes the physician to work efficiently and effectively. Administrators who make an environment where health care can be delivered in a way that is responsive to patient/family needs are essential to Hospice/Palliative Care Programs.

Money. Money is another matter; a very immediate concern. (Timeliness) The Hon. Marvin Moore, the Alberta Minister of Hospitals and Medical Care, is quoted in the press, from a speech made to the Alberta Medical Association. The points Moore makes are relevant to other North American health care policymakers as inflation increases and resources become scarce. Moore's statement is as follows:

> Growth in health-care costs must be limited to reflect inflation and population increase, he

> told the doctors. But trends say costs are multiplying.
>
> "Ten years ago, we processed 250,000 health-care claims a week. This year, we are processing a half-a-million a week.
>
> "The health-care insurance plan in the last five years has doubled from $300 million to $600 million, (in) a time when population only went up by five per cent."
>
> According to a utilization report, the increase came in minor surgery, consultation and diagnostic procedures, Moore said.
>
> Moore said in an interview that he wants "some kind of a system that will see patients signing the bill of what the costs are before they leave the doctor's office."
>
> Hospitals and medical care takes $2.6 billion or 23 per cent of the provincial budget.
>
> "We spend $1,100 for each person each year on hospitalization, Alberta Health Care fees, extended health benefits for seniors, Blue Cross."
>
> Moore said Alberta can afford present health care costs but not the continuation of the 15 per cent per-year increase that has been happening for the past five years.
>
> Moore pointed his finger at patients' over-use of the medical system as a prime cause for skyrocketing medical costs.
>
> "I believe that anything that is free—you walk in and walk out, don't pay a nickel, don't know what it costs—is over-utilized, and I think the over-utilization in the province could be as much as one-third," he said. (_Edmonton Journal_, October 10, 1986, p. B1)

Over-utilization may be a problem. Moore is quoting from statistical evidence about Alberta Health Care billing trends. Moore also quotes from a survey done by the Rand Company:

> "In a survey by the Rand Company, it was found that if the patient pays the bill up front, and the insurance company pays for it later, it reduces utilization by 30 per cent—and with no noticeable effect on the health of the population at all," said Marv Moore. (Edmonton Journal, October 10, 1986, p. B1)

I am reminded, however, of Joe's unwillingness to be involved with the 'System' and Salim's tangle with Administration to get his wife's chart and Mrs. W's fear of being seen as a nuisance or a complaining invalid, and her unwillingness to burden her family with her fears. A strong case could be made that there is an unequal distribution of power between even otherwise competent and assertive patient and family members and Health Care service providers and administrators.

Storch (1986:17) provides an overview of the various ways the health care consumer may be viewed:

> One concept is that of health care consumer as buyer, who is able to investigate the product he is purchasing and to make some reasoned, objective assessment of its value, as, for example, customer to car salesman . . . but for the most part the consumer cannot be as knowledgeable because of the complexity and change in modern health care, and because the consumer is entering into a relationship that is not equal . . . in which the consumer is vulnerable by reason of need.

Storch continues:

> Another, similar concept is that of the health care consumer as a client who assumes a collegial relationship with the local care provider, weighing and deciding whether or not the counsel and advice warrants serious consideration as in a lawyer-client . . . relationship. [However], illness is not generally a planned event, and feeling unwell can impair good comprehension and judgement . . .

Storch (1986:17) makes the case for the concept of patient which incorporates the elements of consumer and client but attends to "the unique relationship that exists between a person and the provider of health care." The concept of patient is a reminder to the System of the temporary imbalance of power between the patient/family and the professional caregiver.

Responsive Evaluation

In the attempt to be fair in the distribution of limited health care resources, how the key actors are viewed is important. If relevant, objective, reliable, and timely evaluation research is to be undertaken in Hospice/Palliative Care, the method of evaluation must allow the researcher to "hover low" over the field (Suransky, 1982:36).

Step One. I contend that we have to turn to the patient and the family for information. What are their needs? Even, what are their wants? What are their strengths? What are their deficits in terms of coping with illness? (Input A)

Step Two. Then care must be taken that the professional seeking information is knowledgeable and able to hear and understand the information that is given. (Input B)

Step Three. Needed support is assessed so that the

System's help may be provided appropriately; neither overwhelming nor abandoning the patient and the family. (Assessment)

Step Four. We have to be realistic. As Marvin Moore says, "We cannot continue to absorb a fifteen per cent increase in health care costs each year." (What is Possible?)

What is Possible is reworkable and an area begging for creative re-thinking and debate amongst consumers and providers of health care services.

Responsive Evaluation that takes into consideration the value of "a smile" to quote Mount and Scott and is based on the foregoing Steps one, two, three and four may become a possibility.

The Responsive Evaluation Framework is depicted as a series of blocks of input information. The original idea for the proposed Evaluation Framework came from a diagram found in the literature before entry to the field (Figure 6). Rough changes were made during the research process (Figure 7).

The blocks were rearranged to "illustrate the interrelationships of various parts of the situation or system" (Lippitt, 1973:86). The first thought was that the 'Client' Population ought to be put at the base in order to reflect or "display abstractly the nature of [the] situation or system" (Lippitt, 1973:86).

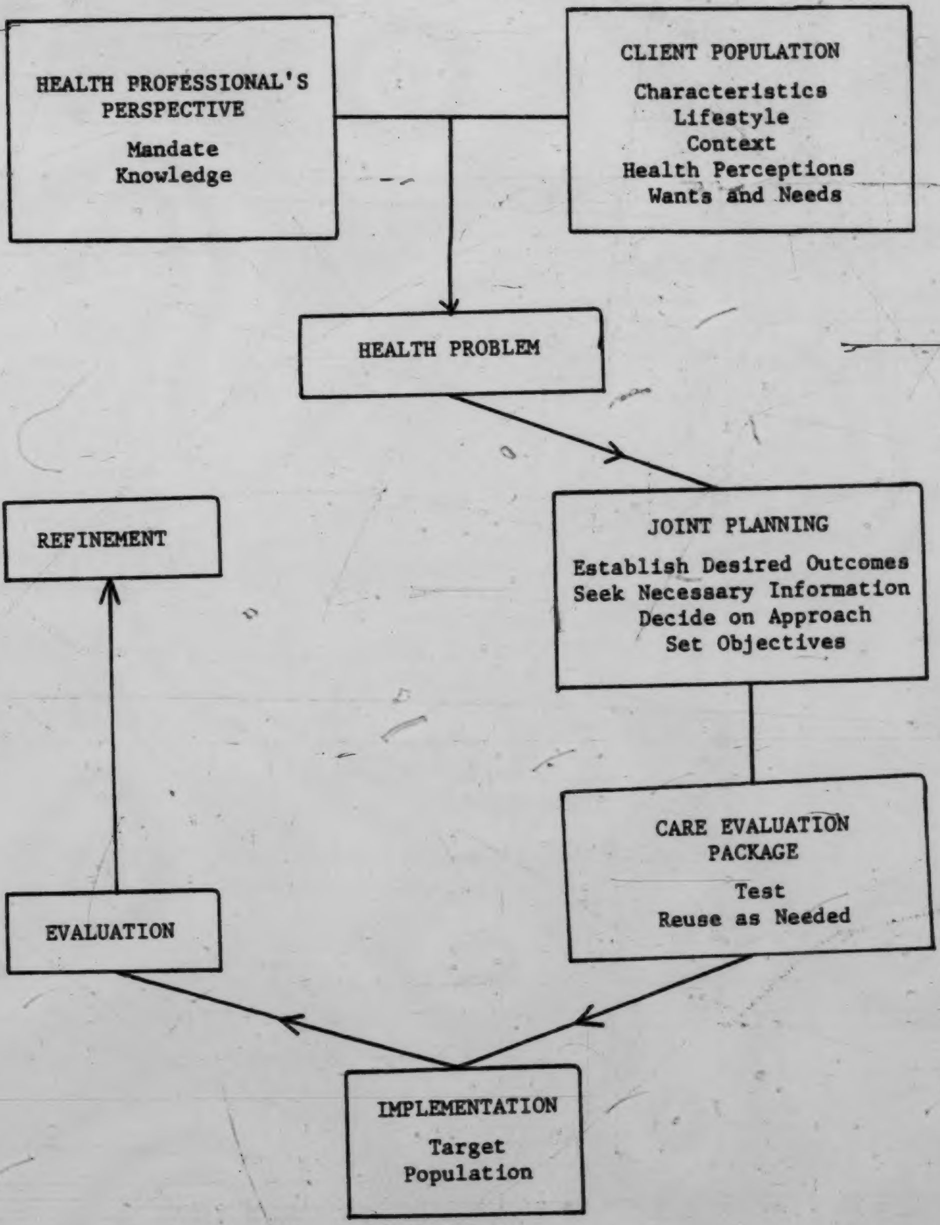
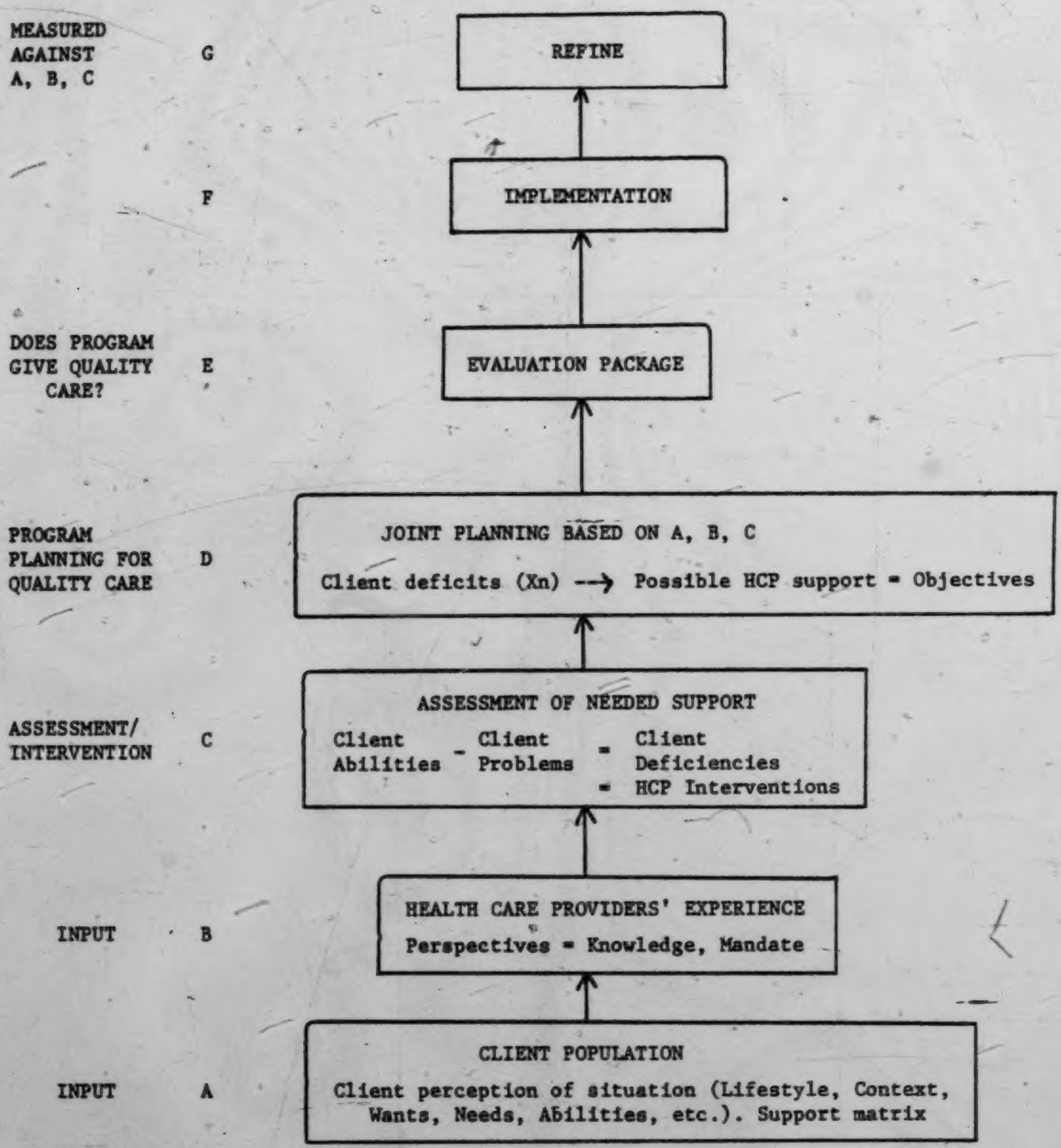

HEALTH PROFESSIONAL'S PERSPECTIVE
Mandate
Knowledge
CLIENT POPULATION
Characteristics
Lifestyle
Context
Health Perceptions
Wants and Needs
HEALTH PROBLEM
JOINT PLANNING
Establish Desired Outcomes
Seek Necessary Information
Decide on Approach
Set Objectives
CARE EVALUATION PACKAGE
Test
Reuse as Needed
IMPLEMENTATION
Target Population
EVALUATION
REFINEMENT

Figure 6

Consumer-Centered Model for Program Evaluation
(Buckingham and Foley, 1978:130)


MEASURED AGAINST A, B, C
G
REFINE
F
IMPLEMENTATION
DOES PROGRAM GIVE QUALITY CARE?
E
EVALUATION PACKAGE
PROGRAM PLANNING FOR QUALITY CARE
D
JOINT PLANNING BASED ON A, B, C
Client deficits (Xn) --> Possible HCP support = Objectives
ASSESSMENT/ INTERVENTION
C
ASSESSMENT OF NEEDED SUPPORT
Client Abilities - Client Problems = Client Deficiencies
= HCP Interventions
INPUT
B
HEALTH CARE PROVIDERS' EXPERIENCE
Perspectives = Knowledge, Mandate
INPUT
A
CLIENT POPULATION
Client perception of situation (Lifestyle, Context, Wants, Needs, Abilities, etc.). Support matrix

Dying Patient/Family = Client
Health Care Provider (HCP)

Figure 7

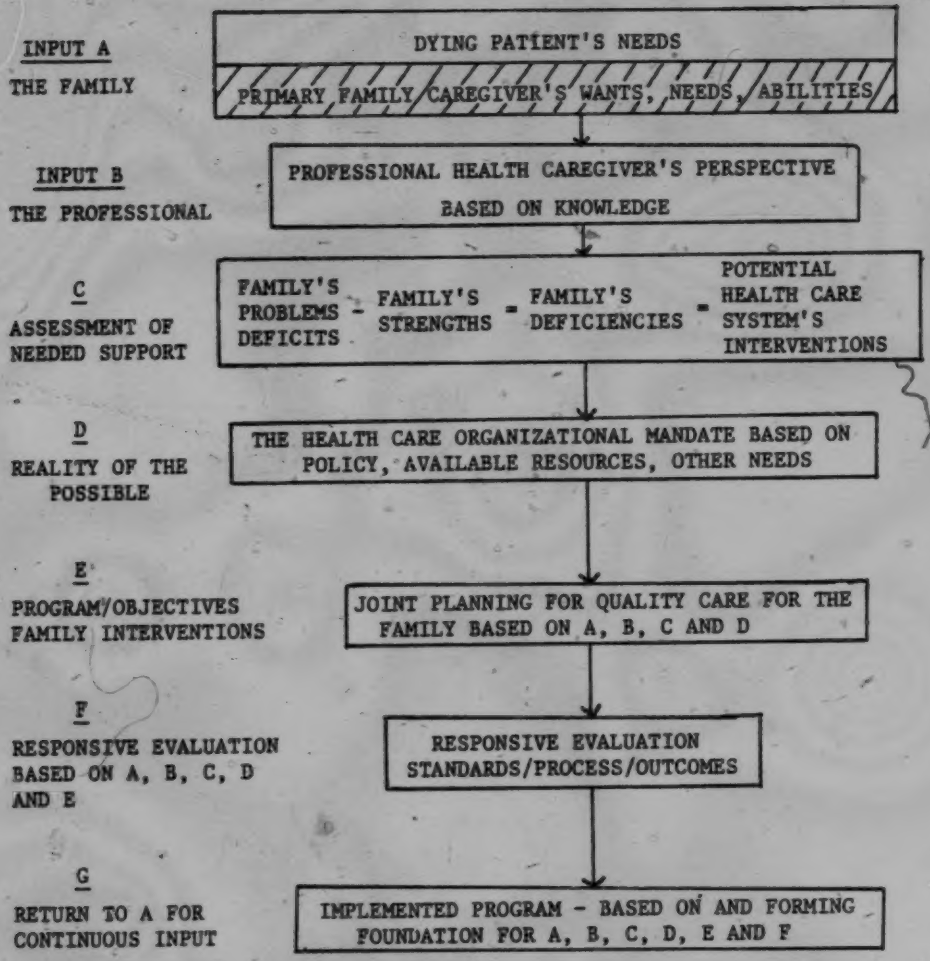
MODIFIED CONSUMER CENTERED MODEL FOR PROGRAM PLANNING
(Adapted from Buckingham and Foley, 1978)

Figure 7 does, in fact, reflect the inductive research process. However, findings from the field and from the literature gave the impetus to develop the model one more step so that the 'client' is now perceived as the 'dying patient and primary family caregiver,' bound together as a unit, with the family caregiver seen as supportive, undergirding the increasingly powerless patient. (It is understood that the increased powerlessness may be only physical deterioration.)

Figure 8 demonstrates that the implemented palliative care program is seen as the foundation (Block G). The size of the program block in relationship to the demands of the patient, family, organizational mandate, planning and calls for evaluation is reflective of the state of the art of hospice care at the present. Block G represents the present heroic attempt of hospice practitioners, administrators and educators to respond to demands that are vast and at times conflicting. Lippitt writes (1973:86):

> The visualized conceptual model, whether physical or graphic, is neither true or false nor complete or incomplete. It is only useful or non-useful. The test of the usefulness of a change model depends on three factors: its realism, its accuracy, and the help it provides.

The evaluation framework is offered in the way Lippitt suggests. It is hoped that the reader judges the model to be simple, accurate, flexible, with clarity


INPUT A
THE FAMILY
DYING PATIENT'S NEEDS
PRIMARY FAMILY CAREGIVER'S WANTS, NEEDS, ABILITIES
INPUT B
THE PROFESSIONAL
PROFESSIONAL HEALTH CAREGIVER'S PERSPECTIVE BASED ON KNOWLEDGE
C
ASSESSMENT OF NEEDED SUPPORT
FAMILY'S PROBLEMS DEFICITS - FAMILY'S STRENGTHS = FAMILY'S DEFICIENCIES = POTENTIAL HEALTH CARE SYSTEM'S INTERVENTIONS
D
REALITY OF THE POSSIBLE
THE HEALTH CARE ORGANIZATIONAL MANDATE BASED ON POLICY, AVAILABLE RESOURCES, OTHER NEEDS
E
PROGRAM/OBJECTIVES FAMILY INTERVENTIONS
JOINT PLANNING FOR QUALITY CARE FOR THE FAMILY BASED ON A, B, C AND D
F
RESPONSIVE EVALUATION BASED ON A, B, C, D AND E
RESPONSIVE EVALUATION STANDARDS/PROCESS/OUTCOMES
G
RETURN TO A FOR CONTINUOUS INPUT
IMPLEMENTED PROGRAM - BASED ON AND FORMING FOUNDATION FOR A, B, C, D, E AND F

KEY

▨ Findings from current study

Figure 8

FAMILY CENTERED EVALUATION

(Based on Buckingham and Foley (1978) and Modified Buckingham and Foley (McHutchion, 1984) based on paucity of assumptions and is considered to be applicable to the situation (Lippitt, 1973:88).

The researcher also claims that the conceptual framework meets Rogers' (1984) criteria of Relevance, Reliability, Objectivity and Timeliness.

Bridging the Gaps: The Educator's Domain

The final pieces of the findings from the inquiry are used to bridge the domains of practitioner, administrator and educator.

I have made the case that although hospice/palliative care has not measured up to the requirements set by quantitative methods of evaluation research, there is 'something' positive about hospice that is sensed by many authors and by the informants in this study. The literature is scanned once more to assist the placement of this final piece of information.

Why, then, if hospice is that good, is there not a palliative care unit in every hospital with a network of home care support staff that provides service throughout the country? Hillier (1985) provides an answer that rings true with the other reality that surfaced from the findings in this study. The other reality is in the domain of the administrator and the educator.

The Politics of Evaluation

Hillier (1985:11) writes:

> By the late 1970's developments to improve the care of the dying were generally accepted, depending on the viability of the proposed scheme, the enthusiasm of the local health authority, and of course, the resources available. But two important events now occurred. The first was a world-wide recession. The second, and more important was the Wilkes Report [the U.K. equivalent to the National Hospice Evaluation Study].

The influential Wilkes Report (U.K.) reflects the tone and the results of the National Hospice Study (U.S.A.). The Wilkes Report concludes (Hillier, 1985:11):

> We do not consider therefore that there would be any advantage in promoting a large increase in the number of Hospices at present and we recommend that the way forward is to encourage the dissemination of the principles of terminal care throughout the health service and to develop an integrated system of care with emphasis on coordination between the primary care sector, the hospital sector and the Hospice movement.

Both the Wilkes Report and the National Hospice Study have an orderly calm about them that appeals to the rational side of oneself. One longs to believe them: to rationalize the memory of the field: play with the data and make them fit into neat typologies.

However, complacency amongst administrators, educators (and researchers) does not fulfill that other mandate that compels the professional to act on behalf of the temporarily vulnerable patient and family (MacDonald, 1979; Lanara, 1981).

The effects of the National Hospice Evaluation Study were reported in the earlier chapters of this report (see also Parkes, 1985; Aiken, 1986; Hays, 1986). The effects of the Wilkes report are reported by Hillier (1985:12):

> Despite a number of useful recommendations, the Wilkes Report stopped hospice development where it could be planned, monitored, and developed within the Health Service and unwittingly allowed development of uncontrolled, unmonitored hospices, some of which may deteriorate into nursing homes of questionable quality.

The question remains: How to bridge the gap between patient/family needs and health care service, between service providers and administration and between administration and government agencies charged to hold the line on escalating health care costs.

Informants' Message to Educators

Palliative Care prides itself on being family centered and has the advantage of being a new component of the health care system. The United States Government, to the chagrin of the National Hospice Evaluation team, endorsed palliative care as a fundable part of the American Health Care System, in a move deemed to be political. The endorsement came before the Evaluators' report was made official and came from public demand.

Academia may be the locus of change that translates the 'grass roots' hospice movement into a major influence on the health care system. Academia has the three-pronged mandate of community service, research and teaching that fits well with hospice philosophy, practice and current needs for credibility and expansion.

Academia is the place where professional caregivers and administrators of the future are challenged and influenced toward the philosophy of care that they will put into practice when they go into the field or return to the field.

The Need to Teach the Hospice Philosophy

Librach (1985:6) asks the question: "Are we listening to the academic needs of our discipline of palliative care? The answer is a definite 'No!'" Librach (1985:7) continues:

> Why do we need an academic base? . . . First, we need to influence caregivers during their training period . . . Second, . . . it is only through scholarship that we shall make our concerns more valid and better defined . . . Third, . . . scholarship is our credibility . . . Finally, I feel that if we are to organize and coordinate our efforts, the nucleus of that effort will be the academic core of our program.

The Need to Include Hospice in Educational Curricula

Mount (1986:1,14) has taken Librach's thesis one step further and has been involved in the establishment of the Canadian Institute of Palliative Care at McGill University. "One of the goals of the forthcoming Canadian Institute of Palliative Care is to urge medical schools to adequately incorporate PC training in their curricula."

Quint Benoliel (1982:ix) writes:

> Surveys of medical and nursing schools suggest that courses on death and dying have not become integral components of medical and nursing curricula.

There are two points-of-view that may be seen as mutually exclusive. One point-of-view expressed by Librach (1985), Mount (1986) and Quint Benoliel (1982) is that there is a need to provide curricula for "health professionals, whose work involves the 'laying on of hands' and the making of decisions of a life-death nature" (Quint Benoliel, 1982:ix). The other point-of-view taken by Roy (1985:3) is that "Palliative care misses its mark if it becomes an island of specialization unto itself."

However, findings from this inquiry show the fallacy of getting stuck in either/or thinking. I contend that the status of hospice care at the present time demonstrates the need for curriculum content devoted to the complexities of providing responsive palliative care to patients and family members. Furthermore, palliative care scholarship need not be an island unto itself but could be a positive influence toward shaping other segments of the health care system toward a more holistic view of the patient as person.

The ideal, the dream for the health care system of the future could be a final bridging, a bridging of the gap between hospice and hospital service modes. The nucleus of the movement toward hospitable care could be the academic core.

Figure 9 depicts the continuation of the development of Hospice/Hospital Care as an ideal. Hospice and Hospital would influence each other and move beyond the territorial preserves of Community Based vs. Hospital Based Programs. The philosophy of both Hospice and Hospital would be translated into hospitable patient and family centered care.

However, the time of confluence has not yet arrived. Until the time of alternative loci of care based solely on patient/family needs and available resources, the work is not yet done. The Hospice way of care is to be considered then translated into programs that for the time primarily serve the dying patient and his family.

The Hospice Way: A Reprise

1. Hospice is a way of caring for the dying patient and family caregiver that provides the complex matrix of support required to meet the identified needs of the dying patient and family caregiver. Moreover, hospice workers are careful in the methods used to identify those needs. We are reminded that what is required is "the hand on the shoulder not the pat on the head."

2. The Hospice way follows the convoluted trajectory

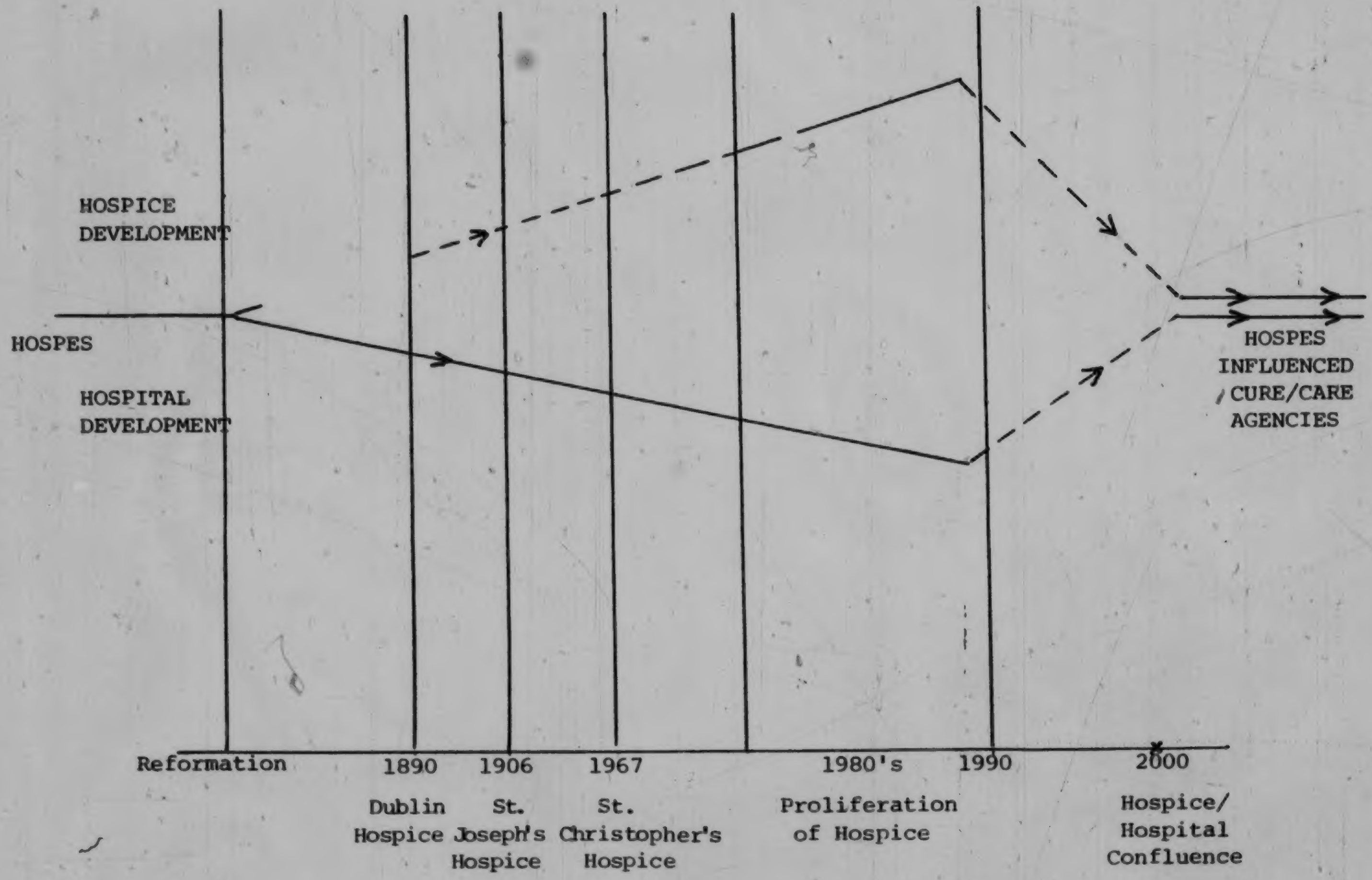

HOSPICE DEVELOPMENT
HOSPES
HOSPITAL DEVELOPMENT
HOSPES INFLUENCED CURE/CARE AGENCIES
Reformation
1890
Dublin Hospice
1906
St. Joseph's Hospice
1967
St. Christopher's Hospice
1980's
Proliferation of Hospice
1990
2000
Hospice/ Hospital Confluence

Figure 9

Growth of Hospice/Hospital Toward the Future of the dying patient and the family caregiver with some understanding that this is the dying patient's first time of being in this place.

3. The Hospice way recognizes the importance of 'small' details. Ignatieff (1984:16) elaborates:

> It is the manner of giving that counts and the moral basis on which it is given: whether strangers at [the] door get their stories listened to by the social worker, whether the ambulance man takes care not to jostle them when they are taken down the steep stairs of their apartment building, whether a nurse sits with them in the hospital when they are frightened and alone. Respect and dignity are conferred by gestures such as these.

4. The Hospice way attends to the holistic needs of the patient and the family caregiver and includes the need for information, appropriately packaged, as part of the hospice mandate.

5. The Hospice way reflects the reality that we are a "society not an economy" (Avorn, 1984). However, it is recognized that an integral part of society is the economy and that hospice must be responsive not only to the patient and family but also be accountable for the resources of time, money and service.

It may be that the work begun by Kübler-Ross, Saunders, and other pioneers in the work of bringing the needs of the dying patient and family to the attention of the public will become a major influence on health care service providers, administrators and educators who are responsible for the future of health care in our society.

Roy (1985:3) writes:

> Palliative care is at a turning point, a moment rife with opportunities for transformation and growth. . . . The ethos or governing perception of palliative care offers clear signals about the kind of transformation required at all levels of medical and health care, whenever professionals and others face the suffering, loss, and impending disintegration of other human beings. This transformation means growing beyond the simplistic posturing fostered by the attitude that hard, scientific medicine, efficient performance, and sensitive presence to people in their drama of suffering are mutually exclusive commitments.

Summary of Recommendations

1. Hospice Concept

- The need for available and accessible information is of paramount importance to family caregivers and dying patients. (Data from inquiry)

- "The very wording of a definition of palliative care will influence its practice, perception by a system, and therefore its impact" (Latimer, 1985:37).

1.1 Therefore, I recommend that the working definitions of Palliative/Hospice care be changed to assimilate the four quadrant model of human needs identified by Kübler-Ross. The addition of the intellectual dimension of human needs reflects the need for information observed during the inquiry.

2. Hospice Research

Evaluation Studies

- Dying patients and family members seek the kind of care that hospice purports to deliver. (Data from inquiry, Mount and Scott, 1983)

- The Greer Study for National Hospice (U.S.A.) showed no significant difference between hospice care and conventional care. (Greer et al., 1986)

- The Wilkes Study for National Health Services (U.K.) recommended that the proliferation of hospice be stopped. (Hiller, 1985)

- Public demand forced funding of Hospice care in the U.S.A. although the funding issue is again up for review. (Fraser, 1985)

- The U.K. hospice movement is growing in a disorganized manner. (Hillier, 1985)

2.1 Therefore, I recommend that a comprehensive evaluation study be launched that uses more carefully selected methods of inquiry. In order to be effective as well as efficient the study must be responsive to the experience of the family and patient ('Qualitative' method of inquiry). Costs, program inventories, and available resources must be assessed and may be tallied using quantitative methods of inquiry.

3. Goals of Science and the Hospice Philosophy

- ". . . science proper is driven by the intellectual desire for complete comprehension." (Lindsay, 1943:32) (Yalow, 1986)

- Reason is not purely an intellectual exercise nor are all drives and purposes merely emotive. (Lindsay, 1943) (Yalow, 1986)

- ". . . without a priori principles there can be no science, nothing but an incoherent collection of facts. But the principles must be supplemented by imagination and by judgement . . . It depends on . . . the fertility of the imagination in producing hypotheses as much as on the grasp of a priori principles" (Kant in Lindsay, 1943:31).

- ". . . all views are to be listened to attentively, since no one is capable of grasping the absolute truth on any subject, whereas all human beings can see different aspects or parts of its reality" (McLeish, 1969:v)

3.1 Therefore, I recommend that the art and the science of hospice care be fully recognized as consistent with the goals of natural science and that energies spent on defending and attacking methods in the domain of research methodology be diverted to developing more finely-tuned instruments that resonate to the experience of the informant. The finely tuned instrument may of necessity always be the researcher in human service research inquiries or to press the point, in any human science endeavour.

4. Hospice and Education

• Many aspects of the art and science of hospice care are teachable/learnable but are not yet represented in practice-oriented professionals' curricula. (Mount, 1986; Mertick, 1986)

• Patients and family caregivers rely on the professional caregiver for help offered in the hospice way. (Data from the study)

4.1 Therefore, I recommend that for the initial phases of curriculum development that hospice or palliative care be designated as a clinical specialty in professional caregivers' curricula.

4.2 I recommend that undergraduate clinicians be introduced to hospice philosophy as it pertains to practice in the care of dying patients and their families.

4.3 I recommend that at the graduate level, clinicians be immersed in hospice philosophy and be encouraged to translate the philosophy into the individual's clinical and leadership roles. Furthermore, practice in interdisciplinary decision making would be enhanced by practica in field settings.

4.4 I recommend that generalizing the philosophy and practice of the hospice way of professional caregiving be encouraged with the end view of having 'hospice-as-specialty' become a redundant concept at some point in the near future.

5. Generalizability of the Findings from the Inquiry

It has been noted that there is a need for further research into evaluation of hospice care as a philosophy, a concept and a way of providing care to patients and family caregivers.

5.1 However, rather than making a case for generalizing from the findings which is always risky when the informant sample is small, I propose that the findings from this inquiry could be 'sliced' differently in another study.

5.1.1 'Loss' is a prevailing theme and the process of living through loss is imbedded in each informant's story. More could be discovered about this 'basic social process' from the findings. Exploratory studies that compare the bereavement experience between those family caregivers who do the major portion of hands-on care could be compared and contrasted with the bereavement experience of the family caregiver who is primarily a care manager. The fact that these roles are not mutually exclusive is basic to the study. Permission from informants to proceed is necessary.

5.1.2 The Family Assessment Form has not been tested in any scientifically rigorous way but the form could be a useful tool to take apart and reassemble to fit unique situations.

- The Responsive Evaluation Framework has served its purpose for this research project. The Framework became a model that kept the patient, the family, the professional and the organizational mandate in mind as decisions had to be taken about ways and means of proceeding with the inquiry. The Framework is offered for others to use in a similar fashion.

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APPENDICES

Pages 386-397 have been removed due to the unavailability of copyright permission.

The material excluded contained Standards of a Hospice Program of Care developed for the Board of Directors of the National Hospice Organization (U.S.A.), November 1981.

APPENDIX 2

ASSUMPTIONS AND PRINCIPLES UNDERLYING STANDARDS FOR TERMINAL CARE

ASSUMPTIONS AND PRINCIPLES UNDERLYING STANDARDS FOR TERMINAL CARE

The International Work Group in Death,
Dying and Bereavement

Introduction

There is agreement that patients with life threatening illnesses, including progressive malignances, need appropriate therapy and treatment throughout the course of illness. At one stage, therapy is directed toward investigation and intervention in order to control and/or to cure such illness and alleviate associated symptoms. For some persons, however, the time comes when cure and remission are beyond the capacity of current curative treatment. It is then that the intervention must shift to what is now often termed "palliative treatment," which is designed to control pain in the broadest sense and provide personal support for patients and family during the terminal phase of illness. In general, palliative care requires limited use of apparatus and technology, extensive personal care, and an ordering of the physical and social environment to be therapeutic in itself.

There are, as it were, two complementary systems of treatment which may often overlap: One system is concerned with eliminating a curable disease and the other with relieving the symptoms resulting from the relentless progress of an incurable illness. There must be an openness, interchange, and overlap between the two systems so that the patient receives continuous appropriate care. The patient should not be subjected to aggressive treatment that offers no real hope of being effective in curing or controlling the disease and may only cause him a further distress. Obviously, the clinician must be on the alert for any shifts that may occur in the course of a terminal illness; which make the patient again a candidate for active treatment.

Patients suffer not only from inappropriate active care, but also from inept terminal care. This is well documented by studies that only confirm what dying patients and their families know at first hand.

These principles have been prepared as an aid to those who have initiated or are planning programs for the terminally ill in delineating standards of care.

General Assumptions and Principles

Assumptions	Principles
1. The care of the dying is a process involving needs of the patient, family, and caregivers.	1. The interaction of these three groups of individuals must constantly be assessed with the aim being the best possible care of the patient. This cannot be accomplished, however, if the needs of the family and/or caregivers are negated.
2. The problems of the patient/family facing terminal illness include a wide variety of issues: psychologic, legal, social, spiritual, economic, and interpersonal.	2. Care requires collaboration of many disciplines working as an integrated clinical team, meeting for frequent discussions and with commonness of purpose.
3. Dying tends to produce a feeling of isolation.	3. All that counteracts unwanted isolation should be encouraged; social events and shared work, inclusive of all involved, should be arranged so that meaningful relations can be sustained and developed.
4. It has been the tradition to train caregivers not to become emotionally involved, but in terminal illness the patient and family need to experience the personal concern of those taking care of them.	4. Profound involvement without loss of objectivity should be allowed and fostered, realizing this may present certain risks to the caregiver.
5. Health care services customarily lack coordination.	5. The organizational structure must provide links with existing health care professionals in the community.

6. A supportive physical environment contributes to the sense of well being of patients, of family and of caregivers.	6. The environment should provide adequate space, furnishings that put people at ease, the reassuring presence of personal belongings, and symbols of life cycles.

Patient-Oriented Assumptions and Principles

Assumptions	Principles
1. There are patients for whom aggressive curative treatment becomes increasingly inappropriate.	1. These patients need highly competent professionals, skilled in terminal care.
2. The symptoms of terminal disease can be controlled.	2. The patient should be kept as symptom free as possible. Pain in all its aspects should be controlled. The patient must remain alert and comfortable.
3. Patients' needs may change over time.	3. Staff must recognize that other services may have to be involved, but that continuity of care should be provided.
4. Care is most effective when the patient's lifestyle is maintained and life philosophy respected.	4. The terminally ill patient's own framework of values, preferences, and life outlook must be taken into account in planning and conducting treatment.
5. Patients are often treated as if incapable of understanding or of making decisions.	5. Patients' wishes for information about their condition should be respected. They should be allowed full participation in their care and a continuing sense of self-determination and self-control.

6. Dying patients often suffer helplessness, weakness, isolation, and loneliness.	6. The patient should have a sense of security and protection. Involvement of family and friends should be encouraged.
7. The varied problems and anxieties associated with terminal illness can occur at any time of day or night.	7. Twenty-four (24) hour care must be available seven days a week for the patient/family where and when it is needed.

Family-Oriented Assumptions and Principles

Assumptions	Principles
1. Care is usually directed toward the patient. In terminal illness the family must be the unit of care.	1. Help should be available to all those involved whether patient, relation or friend to sustain communication and involvement.
2. The course of the terminal illness involves a series of clinical and personal decisions.	2. Interchange between patient/family and clinical team is essential to enable an informed decision to be made.
3. Many people do not know what the dying process involves.	3. The family should be given time and opportunity to discuss all aspects of dying, death, and related emotional needs with the staff.
4. The patient and family need the opportunity for privacy and being together.	4. The patient and family should have time alone and privacy both while the patient is living and after death occurs. A special space may need to be provided.
5. Complexity of treatment and time-consuming procedures can cause disruption for the patient/family.	5. Procedures must be so arranged as not to interfere with adequate time for patient, family, and friends to be together.

6. Patients and families facing death frequently experience a search for the meaning of their life, making the provision of spiritual support essential.	6. The religious, philosophic, and emotional components of care are as essential as the medical, nursing, and social components, and must be available as part of the team approach.
7. Survivors are at risk emotionally and physically during bereavement.	7. The provision of appropriate care for survivors is the responsibility of the team who gave care and support to the deceased.

Staff*-Oriented Assumptions and Principles

Assumptions	Principles
1. The growing body of knowledge in symptom control, patient/family-centered care, and other aspects of the care of the terminally ill is now readily available.	1. Institutions and organizations providing terminal care must orient and educate new staff and keep all staff informed about developments as they occur.
2. Good terminal care presupposes emotional investment on the part of the staff.	2. Staff needs time and encouragement to develop and maintain relationships with patients and relatives.
3. Emotional commitment to good terminal care will often produce emotional exhaustion.	3. Effective staff support systems must be readily available.

*The term "staff" in this document includes salaried and unsalaried (volunteer) personnel.

These assumptions and principles were prepared by members of the International Work Group on Death, Dying and Bereavement at the 1978 Conference in Asilomar, Calif. The Work Group first met in 1974 when members decided to begin work on standards of care essential in the care of dying patients. Because of the rapid growth of the Hospice movement, the group has released its work to date on principles and assumptions underlying standards so that others can use them now. The members were:

Ina Ajemian, M.D.
Donna Bettes, M.N.
Esther Lucille Brown, Ph.D.
Robert Buckingham, Ph.D.
Loma Feigenberg, M.D.
Zelda Foster, M.S.W.
Robert Fulton, Ph.D.
Alice M. Heath, M.P.H.
Barbara Hill, B.A.
Jeffrey Houpt, M.D.
Richard Kalish, Ph.D.
Robert Kastenbaum, Ph.D.
Bernice Kastenbaum, R.N., M.S.
Priscilla Kissick, M.N.
Sylvia Lack, M.B., B.S.
Ida M. Martinson, R.N., Ph.D.
Douglas McKell
Balfour Mount, M.D.
Colin M. Parkes, M.D., F.R.C.Psych.
Cicely Saunders, M.D., O.B.E.
John Scott, M.D.
The Rev. Kenneth Spilman
The Rev. E. Carleton Sweetser, M.Div.
Richard J. Torpie, M.D.
Mary L. S. Vachon, R.N., M.A.
Henry J. Wald, P.E., M.S.Arch.
Thomas West, M.D., O.B.E.
J. William Worden, Ph.D.

Task Force Chairman:
Florence S. Wald, M.N., M.S.

International Work Group on Death, Dying and Bereavement Chairman:

John E. Fryer, M.D.

APPENDIX 3

APPROVAL FOR ENTRY TO SUBURBAN HEALTH UNIT

SUBURBAN HEALTH UNIT

Box 92
3455 Dolmay Street
Downsview, Alberta T3J 7J4

1984 05 15

Edna McHutchion
10249 - 133 Street
Edmonton, Alberta
T5N 1Z6

Dear Edna:

The summary of your proposed study The Family Perspective on Dying at Home has been reviewed by Dr. ________. Approval has been given for the Home Care program to participate in this study as outlined in your summary. In addition the staff have reviewed the proposal and are looking forward to their involvement.

Dr. ________ expressed interest in meeting you at some point. Could you contact me with a convenient time?

Yours sincerely

Joan Boswick, B.Sc.N.
Director of Home Care

JB:dr

APPENDIX 4

FAMILY CONSENT FORM

FAMILY CONSENT FORM

A FAMILY PERSPECTIVE ON DYING AT HOME

Edna McHutchion, R.N., B.Sc.N., M.Ed., Doctoral Candidate
Faculty of Education
University of Alberta Telephone: University, 432-5241; Home, 452-8259

This study concerns the experiences of caring for a member of the family who is receiving palliative care at home. The results of the study may be published and will become part of a doctoral dissertation. I anticipate that these results will assist in developing greater sensitivity among those who work and plan home care for palliative care patients and their families.

Participation in this study involves having the investigator visit with you in your home for approximately two hours. Two or three subsequent visits would be arranged at your home or some other mutually agreed upon location.

During the visit the investigator will invite you to tell of your experience of caring for your ________________. Talking about the experience may cause you some discomfort. However, a possible benefit is that talking about your experiences may prove to be helpful to you. You may ask questions of the investigator at any time about your participation in the study and you may withdraw at any time without in any way jeopardizing the care you receive.

You or your family will not be personally identified in any report or publication of this study. Although the visits will be taped to assure accuracy, names will be removed from transcripts and tapes will be erased on completion of the study. To further ensure confidentiality, this form will be kept separate from the transcripts and all materials will be kept in a secure, locked location.

Thank you for your help with this important work.

______________________________ ________________
Signature of Investigator Date

The study above has been explained to me and I have had an opportunity to ask questions. I have read the above, understand it, and voluntarily consent to participate in this study under the terms outlined.

______________________________ ________________
Signature of Participant Date

APPENDIX 5

SAMPLE OF PROBE QUESTIONS FOR KEY INFORMANT AND SAMPLE OF MEMOING

SAMPLE OF PROBE QUESTIONS FOR KEY INFORMANT

These probe questions were used in the fourth interview with Jennie. The fourth visit took place at SHU after the death of Mrs. J.

The change of environment from home to neutral territory made the questions seem less offensive. However, the questions were used in an indirect manner serving more as a check-list than a directed interview.

The question was couched in a preamble from the data that had already been provided in previous interviews.

About Pain Control

Preamble:
- Morphine - injectable - now at drug store
- Codeine - holiday weekend - shortage of medication

Question:
- What did you have to do in order to cope?
- What were your feelings?
- What would you suggest for the future?

About Multiple Stresses

Preamble:
- Life goes on out there - no normal routine.
  e.g. Debbie needed exact change for school the next morning. Baby needed feeding at 2 p.m. etc.

Question:
- How was that for you and the family? Any conflict? How do you deal with it?

Gathering of the "Clan"

Preamble:
- You needed to buy extra sheets - energy channelled to meet their needs.

Question: - How did it help to have the extra family? Did it cause any problems?

Finishing the Marathon

Preamble: - You were the coordinator/caregiver for 2 1/2 months, night and day. You were "bone-tired" when Sara came. Sara and George sat with Mrs. J the night she died.

Question:
- What were your thoughts/feelings when you were awakened?
- How did people recognize your contributions?

Support Matrix

Preamble: - You gave full marks to Laurie and Theresa. There were other helpers too.

Question:
- Who were the most necessary?
- Where were the gaps?

Changing Relationships

Preamble: - Your feelings toward Mrs. J changed over time. For example:

Before	2 1/2 months	Death	Now
Divisive	Helping her with everything from bathing to answering her bell day and night		
Question:	When did things change? Why do you think things changed?		What remains? What are your feelings now towards Mrs. J, George, children, nurses, homemaker, doctors?

Your Physical/Emotional Health

Preamble: You didn't get much sleep or sit down to meals, etc.

Question: How do you manage to mesh you needs/ Mrs. J's needs?

Preamble: You mentioned you sometimes felt nervous. You slept with one eye and one ear open.

Question: Were you "on duty" even when others were in the house? What did you see that needed to be done that you could do? Couldn't do?

Preamble: Sometimes when I visited we laughed about things even though the situation was serious.

Question: Did you have any good laughs? Good cries?

Expectations of Health Care System

Preamble: You said that physical needs could be met in the hospital.

Question: What is missing that could be provided at home?

MEMOING

Introduction/Context to the Memo

I wrote myself a memo October 24, 1984. The heading is Mutual Trust. I had just come back from hearing Nan's concerns about Joe's ability to do hands-on-care that she was sure would be necessary in the future as her condition deteriorated. There was evidence of a distinct lack of mutual trust in the possibility of dying at home with comfort and dignity. Some of the comments give context to the final analysis and judgement that I made in the memo.

The memo is recorded here as it appears in the field notes with the exception of names changed for purposes of confidentiality. The memo is inserted here for two reasons:

One: The content explicates the analysis of the patient and family needs and the complexities inherent in understanding those needs.

Two: The transcription provides an example of the memoing process that was a constant and continuing part of the research process.

MEMO 1

October 24 Mutual Trust Dying at Home

Joe thinks he can do it.

Nan doesn't think he can
- doesn't have much faith in the system (past errors)
- doesn't want to have family do all the undignified physical care that she knows will be required - lived with dignity - let me die with dignity.

Joe hasn't even thought of what he'd need
No experience in delegating
Autonomy - Perfectionist

Help - No faith in the 24 hour service
"I wouldn't be able to wait"

MEMO 2

Seems to be worried about
  Pain & symptom control
  consultative team
  daily - 24 hr care prof. level
Pt. wants comfort & as much dignity as poss.

"Contracting with Client"

1. Client doesn't know what services are available
2. Client socialized to 'need' professionals - sterile walls - cure care - 24 hours availability
3. Find I'm tapping into my old network of people who will get involved
4. Move to change label from Home Care Nurses to H.C. Coordinator

[Item 4 gets at a controversial issue in Home Care re role of home care nurses: Should home care nurse assess needs then contract work out or do the hands on care?]

Oct. 25
Called M____ re request for info re Memorial Society
M____ understood and responded.
→Need for unclutteredresponse.

MEMO 7

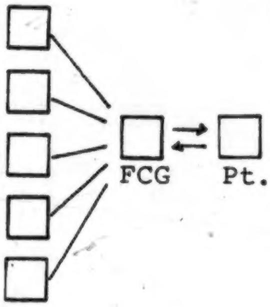
Conflict between

→ Pt. time - "I want to live today fully - I don't have much time + F.C.G. [Family caregiver] I have to live in the future as well

Can have all the support services in the world but if you don't have 2 main actors pulling in same direction - forget it.

→ Need for Intensive/Extensive Care

→If the 2 main actors don't feel OK about it all the back-up in the world won't pull it off



Need family conference? Thanksgiving [weekend] would have been ideal.

MEMO 5

Two pages over from the last notation I have pinned a note written in a frail "spidery" hand. The note was given to me by a person who knew of this study and said "How about this? What if they won't have help?"

May 10/84

B________!

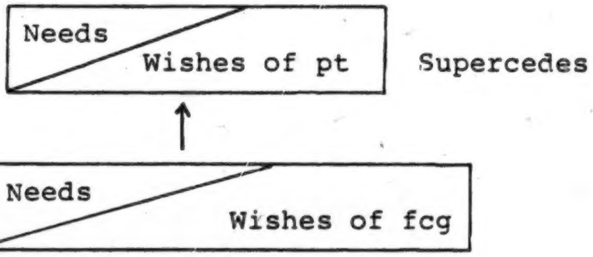
Just in case you were thinking of coming here I thought I better write to let you know I do not feel up to having company.

Even my family realize this too now so you have to forget about it too!

H________
[a dying person]

MEMO 6

Several pages later



Letting go

acceptance of terminality of pt.
∵ [therefore] can help fulfill

Not Letting Go

letting go of own

- inadequacy
- fears
- surrender to a greater ideal: to the wishes of the dying person—doubt—

MEMO 3

On the opposite page I had put

Joe & Nan Oct. 24/84

Difficulty of home care

"An eager public often overlooks the complexity of providing hospice home care." p. 45, Creek, 1982.
To patient-family caregivers -
- family members' intense, sometimes conflicting feelings.

Focus-spouse	usually spouse (53%)
	adult child 33%
	other 14%

MEMO 4

On the next page under Research Process

October 24/84

- If research is only brain but no heart it lacks vitality

- If research is all heart and no brain it lacks credibility -

- Balance -

APPENDIX 6

RESUME OF QUALIFICATIONS

RESUME OF QUALIFICATIONS

Edna McHutchion

PROFESSIONAL QUALIFICATIONS

Registered Nurse

Alberta Association of Registered Nurses

Chartered (Certified) Psychologist

Psychologists' Association of Alberta

EDUCATIONAL QUALIFICATIONS

M.Ed. Department of Educational Administration
Faculty of Education
University of Alberta
Edmonton, Alberta

B.Sc.N Faculty of Nursing
University of Alberta
Edmonton, Alberta

Faculty of Nursing
University of Toronto
Toronto, Ontario (8 credits)

RN School of Nursing
Hamilton General Hospital
Hamilton, Ontario

RELATED WORK EXPERIENCE

Designed, developed and implemented Community-Based Support and Educational Bereavement Program for Families and Professional Caregivers in cooperation with Program Director at Family Service Association of Edmonton. Included over 200 home visits for purposes of family assessment and interventions.

OTHER RELATED ACTIVITIES

Committee Member, Community Liaison, Palliative Care Coordinating Council.

Founding Member, Hospice Care Edmonton Society.

Comprehensive Care for the Dying: An Organizational Model. Master's Project, Read and endorsed by Elisabeth Kübler-Ross.

APPENDIX 7

SALIM: PARTIAL TRANSCRIPT OF VISIT AFTER NADIA'S DEATH

Transcript is included to demonstrate the way Salim attempted to resolve Nadia's death.

SALIM: PARTIAL TRANSCRIPT OF VISIT AFTER NADIA'S DEATH

Salim It was—that's strange enough on the day of her death. You know, I slept overnight there. Remember I was telling you about the car and how the car was not—I was not doing anything about the car. At nine thirty, okay, I was sitting there, nine thirty in the morning, so I figured, okay, maybe it's a good time to go and have a quick grease job on the car. Because I was thinking—I thought things will . . . may as well if I'm sitting here, might as well go. And then I got there . . . out for half an hour and then I did go. I changed the oil on the car and I got a quick grease job. You know, this fast service stuff.

By ten fifteen I was back. But actually at that time I had no conception that she would be going that fast. I was bored in the hospital because there's so little you can do. But I wanted to be with her and then I was thinking about going. Imagine if she had died at the time, I would be blaming myself even more. Like I was going to go and change the car oil and she was dying. You know, like, it's—

But I thought, okay, maybe might as well make use of this time, you know, to do something like that because I was not going to work on the day at all, so . . . might as well do something like that, which was three months overdue. It was the situation with me because, you know, I was, you know, like I was looking at other patients in the hospital. They have some system, you know. I was going out and talking with them, you know. Actually I came to know quite a number of them. They had a system because there are maybe a mother and father and sister and couple of brothers and husband and wife or you know, there's six, seven at least very close family involved with one person.

R They can spell each other off.

Salim Yeah. They were doing that very nicely and they'd say, okay, we'll come in the morning, then you know—so it was sort of actual care to—you know, they were caring for the patient. They're having their own things to look after. And they . . .

it was okay for, you know, for something like three, four hours, sitting with the patient and [then] going completely—thinking about their own life. And do things, you know, normal routine. For me, for me it was really difficult, you know, like either I am with Nadia or nobody's with Nadia, you know, so it's—and then here I have the children too, you know, I have to look after. So it was, it was sort of extremes [pause] too much need, you know, on my time, or too much demand on my time and I know in either way I am that other person is suffering. Like if I'm leaving the children maybe they are not—although I, you know, I know that for children I can make up for that somehow but with Nadia I know the time was running out.

R But still you were pulled.

Salim Yeah.

R Always pulled.

Salim Exactly. Yeah. Like even now I'm feeling guilty that at times I was sneaking here and there at times to go and maybe fix the—and . . . without pressure, you know to get the car done or do this or do that. Now [I think] maybe I shouldn't have done that. Maybe I should have, you know. Nothing would have changed or something but—but definitely I didn't feel good and still I don't about that I was not with her at the time of her death. I wish I was there. For her and for me. It would have been equally needed for me, that I would be there, were there. You know, I need that maybe more than her even.

R Um hum. [Pause]

Salim Like even—I was telling that friend, you know . . . I wish he was not there at the time because . . . I'd have been with Nadia. [Pause] But you know—because definitely—like Nadia was very [pause] again she was putting maybe a front also I think all the time. I think she was. I think she was afraid, definitely she was. You know and especially at that time, I don't know how a person feels, you know. Definitely she was very scared of—been afraid. And I know she looked up to me that, you know, I had to comfort her. And I, I just—if I were there maybe it would have been a little bit more comfortable for her at the time.

Because to me, I don't know how a person feels really at the time. That, which I will never find. Find out, you know, how she was feeling. I don't know. [Pause]

I guess we'll never know for sure . . . somebody was watching I think it was a movie or documentary, I think it was a documentary about the people who clinically have been classified as dead. I haven't watched the movie, the show, but he watched it and he was telling me about it. Actually he was telling me about it the day of Nadia's burial. He was sitting there, he was telling me about how people feel they are going through a tunnel and the light and after that, you know, a room all light, almost . . . you know.

R Um hum. [Encouraging Salim to continue.]

Salim I don't know. I really don't know what to make out of this but he was telling me that to comfort me, you know, that things are not really that bad and she must be in some nice place now, something like that.

R Um hum.

Salim Which I hope she is. [Pause] And all this, you know, all this talking about—it's mysterious, you know, it will stay a mystery until a person himself dies. To find out. Like all this talk about the spirit hangs around for maybe some time and she could be with you or, you know. I really don't know. You know, all those things are very—I don't know, it's just— [Pause] Like she was buried on Friday and on Sunday, although the weather was very bad that weekend, it was raining quite a bit, I took the children there. And I went there. I stopped the car just there and it was very muddy.

They made a mess of themselves. And I let them go. Actually I took a camera. I took a picture of them there. I don't know why I did that but it was—I was sitting watching what they would do. Joel was running around, you know, but Ellen, she was crawling, making a mess of her clothes but I just let her do that. She crawled up to the grave. Of course the grave had flowers all over it. Maybe that attracted her. But I was looking, just wondering, you know, is there anything—

always, you know, the after life is mystery and it's an old mystery and I will never understand it. I don't know, that could be the whole thing is just coincidence and at one time I think maybe the whole thing is just a physical thing, you know. Physical phenomena and there's nothing after and then there's always [pause] like in our faith [Moslem], we very well follow the Christian beliefs and life after death and judgement day.

And going to heaven or hell and you will be judged on your things—you know, pretty well the same. Sometimes I wonder if that is the case or not. Honestly, you know, I don't know. It could be that—it or the whole universe is just, you know—something dictated by another bit of physics. And things happen at random, like, you know, whatever's happening to everybody is just—with no [pause] I don't know. I guess I'll find out when I die. [Laughs] What will happen. That's the only way to find out for sure. [Pause] (Reflecting on the spiritual)

At times I wonder, maybe [Nadia] was never sure that she was going to die because a couple of days before she died, I asked her, . . . do you want me to bring the kids? And she said oh no, no, I am very drowsy now because my calcium's high. Wait until it goes down a bit, maybe you bring them so I can enjoy them. But—and, you know, that didn't happen of course. But [pause] so I, like, I knew at the time that, you know, her case is really, is not going to improve. She didn't want to see the kids although I took them the Sunday before, you know. I took them the Sunday before without her even asking for. I just took them there and that was the last time she saw them. The Sunday before.

R And it turned out well.

Salim Yeah. Yeah. And actually she enjoyed them. Yeah, you know, Sunday—we talked about it maybe on Monday, yeah, so that was the last time I took the children to her. But after that she didn't want to see them again and I did not have a chance to take them to her.

It's not easy to really put things in perspective. Like I don't know, definitely [pause] we were maybe—maybe I was aware that she was very close to the end and I [pause] and I'm being helpless also and not knowing what to do.

R Um hum.

Salim And all this kind. She was not really admitting to anything because we never really discussed it. We did not discuss her potential death. That it could be happening any day. Although it was happening. [Pause]. But like [pause] maybe we did it the best we know and that's maybe the best for us too, you know, like even—there's a lady called N_______ there, she was very supportive. She is a nurse by profession and she is also looks after patient needs. Whatsoever. She was asking me, you know, like I went to her room—one day, she said come on, and she said, okay, maybe you want to discuss anything with Nadia? the situation? You know . . . she's dying. [I said] . . . I don't really want to talk about anything particular. Like, you know, all the books say, okay, said, okay, here she's dying, so, okay, now maybe you have . . . twenty-four hours . . . if— . . . I never—

I never had the strength even to discuss it. I was just avoiding the whole thing with her. She was avoiding with me. Actually in her statement(?) she seems as if she was still hopeful that things may improve.

R Like "I'll see the kids when my calcium gets under control"?

Salim Or something like that, yeah. You know, it seemed to be like that you know.

R So—

Salim So we never sat down and discussed that she is dying. We never did that. [Pause] I knew that that's happening. I don't know if she knew exactly or not.

APPENDIX 8

THE HOMECOMING: JENNIE'S EXPERIENCE

(Transcripts 3:2:21,22,23)

THE HOMECOMING: JENNIE'S EXPERIENCE

Sara arrives at 10:30 p.m. from the airport carrying confusion, liveliness and treats for the family. She had not yet had her dinner and everyone was scrambling. The transcript reflects the tempo of life in the kitchen just down the hall from Mrs. J who was sleeping comfortably. It was impossible from the tape to sort out who was saying what. But then I was there and I had difficulty sorting it out as well. Confusing reality.

I had been invited to meet Sara and Jennie had been talking about caregiving so I was taping Jennie's comments when the family arrived. (Transcripts 3:2: 21,22,23)

Family enters one by one:

? Did anybody phone?

Jennie Jim.

? What time is it?

Jennie Debbie, have you met Mrs. McHutchion?

Debbie Yeah.

R Hi.

Jennie This is my youngest daughter Debbie. He phoned about ten minutes ago.

Debbie . . .

Jennie Hi.

R Ah, this is—

Jennie Louise.

R And . . .

? . . . keep her [Mrs. J] awake.

Jennie This is the first time she's [Mrs. J] ever been this tired.

R She is just really whacked.

? Where's Auntie Sara?

Jennie . . . getting some things from the car. I told Debbie to get them.

R Oh listen, your company's here.

Jennie Just a second and I'll—[tape off]

Jennie Sara says she's [Mrs. J] lost a lot of weight since she was here last. When were you here last?

Sara I left on the twelfth.

Jennie Twelfth of July?

Sara I came out on the fourth and I left on the twelfth.

Jennie August.

? Where's that bag?

? Oh here's—

Sara Blueberry jam, greengage jam, bottle of raspberry juice, bottle of blueberry juice, a bottle of grape juice. Juices— [noise]

Jennie Oh I left it at the door.

? The big heavy one?

Sara And two cans of curry sauce. China Lily curry sauce that you can't get in Alberta.

? Aunt Sara's going to make the hamburger. What am I making?

Sara The soda, sundae.

? I'm making the sundae.

? There it is.

Sara I'm going to show her [Debbie] how to do these things.

R Oh great. [Floundering in the change from serious interviewer to participant observer.]

? What type of work is that?

R Cross stitch.

? It looks really easy.

Jennie Oh yeah. I used to make cross stitch cushions when I was a kid.

? I emptied your bag out.

? So you brought some home-made juice.

Sara Yeah. Home-made juice.

R Oh that should be good.

Jennie Maybe grandma will like that.

Sara That's what I thought. (Comforting food for the patient)

? I've got one.

Sara Got one what?

? One of these—this must be yours.

R Oh this looks complex. [More crafts] So which . . . are you doing this for?

? I'm doing the . . . sundae. Put it in [the baby's] room, she's doing the hamburger.

? . . .

? Yeah, I got some cinnamon buns and stuff.

Sara . . . tell me what you're . . .

R Yes.

Jennie Yeah, this [research] is interesting, so you'll have to listen here for a couple of minutes.

? Here's your change.

Jennie Oh, okay, thanks.

? Do you want a cinnamon bun or a— [tape off] (Food is part of the family gathering)

Tea and coffee served. Sara was fed. Sara was quite opinionated. She expounded on B.C.'s welfare system.

Sara It's like when you go to adopt, the social worker pops in unexpectedly to see what you're doing at lunchtime—are you having lunch or are you lying on the couch in your housecoat, right? And they do this quite frequently before they decide to let you have kids. But there you are on welfare, with kids, and they call and make an appointment and, of course, the house is going to be spotless and the kids are going to be clean and in their best clothes and sitting on the couch reading Time magazine.

R And they're only three. [Laughter]

Sara Watching the news. [Laughter] Walter Cronkite. (Talk about other issues than the reason for the gathering)

Everyone was getting quite wound up. When it seemed that some more focus on Jennie's experience was forthcoming I switched the tape back on. But everybody just talked like families do when they gather for ritual purposes.

Much later Jennie gives a succinct explanation of the problem of generalizability of the inquiry as well as addressing steps D, E, F and G of the proposed CLIENT CENTERED EVALUATION MODEL that was being developed for this document. Jennie turns to me:

Jennie But you know, I—it's just like this type of work that you're doing now—you're basically a researcher.

R Um hum.

Jennie Wouldn't you say?

R Um hum. Yes.

Jennie Okay. So you're researching this particular problem of having somebody die at home. So what you see here in this house—it might be different in somebody else's house. I mean every—what I'm trying to say is, every case is different.

R Um hum.

Jennie And that maybe the rules haven't been flexible enough—

Sara To accommodate—

Jennie In all government health organizations.

R Um hum. (Every case is different: Need flexibility in response) (3:2:33)

APPENDIX 9

LETTERS FROM ALICE TO HER FATHER

Nov. 26

Dear Dad,

I'm coming down to see you this afternoon, but, since Mom's home because it is her day off, I suspect we will not talk. So I am writing because I have a few things I need to say.

I had planned to come down earlier this week, because this is my last week for the car, next week I don't have it. One day I phoned, and when there was no answer, I didn't drive out. Maybe I should have. I feel funny about coming to see you, partly because of my own recent actions, and partly because I know I don't bring you too much joy.

The shame you suggested I should feel that Friday night two weeks ago I am beginning to feel, and that makes it harder for me to face you. Add to that the fact that I can't stand to look at your lip, whether it is bandaged or not, and you see I am a coward. What can I do for you anyway? The one thing you want from me, that I quit bugging you about your lip, I can't do. That's all that matters to me right now, and there's nothing else I want to talk about, or think about, until that's looked after. One-tracked minded, that's me.

Have you made an appointment yet? Are you going to? Do you want me to?

Georgina and Charlie and I are no longer in communication about this problem. We are so much in disagreement that it requires a parting of the ways. I guess that is the same way you broke off with Mabel for eighteen years, over a decision involving your parents.

When my own life has been tough, I have been inspired by your courage, and it makes me feel shaky to see you giving up like this. I need you to pretend to be brave, for my sake if not for yours. I know I should be a big girl now, and I can pretend for my own children's sake, but there are still all those times in the dark stillness of the night where I need you to remind me that the struggle is worthwhile, that we live for some reason, not just some accident of nature. And after all, Dad, why should I or anybody live? What am I to go on to? Endless suffering? Why not end it now? I've been suicidal since I was 18. At least you had a few decades where you thought things were O.K.

You always remind us of the value of the family, in deeds as well as words. And I understand that you feel strongly about the people you like that just being with them wears you out, whether it is joyful or painful. So I don't expect to see much of you. Never have. Even though I needed more. I have the same affliction and I can't stand too much of anything, and I can stand the painful better than I can the joy. So in a way, I keep myself in pain, by choice. Maybe you do too. But this pain of yours is more than I can bear, even if you can handle it. And I am asking you, one more time, to have your lip treated for my sake, or for God's sake, if not for yours.

I know you think I'm pushy. (Georgina says I'm heavy-handed). I'd rather be heavy-handed than pussy-footed. All this summer I was crazy with anxiety over you. Then I pushed into your bedroom and I was depressed and sad. Now I'm mad.

Love,
Alice

Jan. 17

Dear Dad,

For Godsake Dad, why are you punishing us so cruelly? We understand that you wish to be left alone, even to die, but don't you see we love you and want you to live? For our sake, if not for yours. You may think that is selfish, but what would you do in a similar situation? What if you were me, and the tables were turned?

Nobody can reach you anymore. Are we all inhuman, that you don't hear our plea? Or are you? Are you punishing us because we don't love you properly? Never did? O.K.—that's enough. We've learned our lesson. Lay off!

You may not feel this is true, but you're the one with all the power. It's your card game. You're the dealer. I understand your message. Stay in the game and lose, or get out and lose. Why are you refusing treatment? Why are you cutting yourself off from us? Why are you punishing us?

I wanted to write and tell you that I love you, but the minute I start to write, I'm hopping mad. I go crazy thinking about you, alone, sick, in pain. You interpret our love and concern as intrusion, invasion of privacy. That's a dirty rotten trick.

I would like to hear from you, but I'm scared to look at your lip. Write me a note. Tell me you've agreed to go for treatment. That's what I want to hear from you. Please, Dad.

Love,

Alice

Jan. 22

Dear Dad,

This is Alice again. I typed the envelope because I thought you might not open the letter if you knew it was me pestering you again.

I am going to quite bothering you Dad (well maybe I'll write another letter or two) because we are wasting your time and energy resisting me. If that lip goes any longer treatment won't be effective and you will certainly die.

No one is planning on picking you up against your will, because treatment without your approval is out of the question. Please take off your cowboy boots, don't worry about locking the door, and have a good rest, and then please get up and go for treatment. And don't wait too long. You haven't got much longer—it won't respond to treatment if you don't go soon.

No one else is really causing you any trouble but me. Mom won't cross you. Charlie washed his hands of it. Georgina will be whatever you want. I'm your only enemy, and now I'm laying down my weapons, puny and useless as they have been.

If you let this go until it is too late, I will even bring you rum, because I love you. But I won't yet, because I love you. If it comes to that, it will break my heart. You don't have much time to waste.

It's hard to understand what your position is—this is like a terrible card game being played in a runaway caboose. I don't like it. Phone me. I will go to the doctor with you, any time.

Love,
Alice

Jan. 31

Dear Dad,

I don't have much hope that you will read this letter, as you haven't opened my last one yet (I check with Mom). I didn't think you would be able to figure it was me when I typed the envelope, but maybe you do have intuitive powers, as Georgina claims.

I have to talk to you about the one incident that goes around and round in my mind, and gives me no peace. It was the day you asked me to come down and help you get some of your affairs in order before going into the hospital, and I wrote down a few things for you regarding who you wanted to have various things of yours. That part was difficult, but necessary, and I could handle my feelings. But later, when you had been drinking a little, and your feelings came closer to the surface, it became painful for me. As I mentioned before, I was honored that you wanted me to have some of your more precious books, but even more, I wanted you to get better and keep them yourself for a long time.

What was painful for me was when you showed me and gave me the book you made, with the little boy in front, the little boy walking down the railroad track, and the picture in the back of older men, standing in line. I think that book is beautiful, and that it truly represents you and the things you have cared about, your love of nature, and what is natural, your love of children, and your concern for anyone who is not a child anymore. I don't know if you remember, but everytime you looked at that book, you began to cry. For me, that was too much, but I didn't break down, though I felt like it. Since then, whenever I begin to think about it, I feel like crying.

It's not my feelings I'm concerned about, but whether you knew how beautiful that book is. Of course you know, because you created it, but it did touch my heart, and would melt anybody's, I'm sure.

Well now, why did I have to tell you that? I always feel that you don't believe that we love you, and I wish I could reach through to you and convince you, somehow. Maybe I thought telling you how I feel about the book would do it.

I still can't believe all this is happening, for my mind and heart fight against the facts. To think that it's come to this....unbearable. Please Dad, please go get some treatment before it's too late.

Love
Alice